ORTHODOX JEWISH NURSES ASSOCIATION

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THE AMERICAN NURSES ASSOCIATION (ANA) WELCOMES THE ORTHODOX JEWISH NURSES ASSOCIATION (OJNA) AS THE LATEST ADDITION TO ITS LIST OF ORGANIZATIONAL AFFILIATES.

full press release on page 26

Genetics

Jewish Genetic Disorders

BRCA and the Genetics of Cancer

The Ethics of Knowing One's Genetic Risks

OJNA LEADERSHIP

Mission:

The mission of The OJNA Journal is to

- Provide timely news and research updates
- Relay evidence-based research
- Share OJNA news and updates

OJNA Mission Statement:

The Orthodox Jewish Nurses Association was founded in 2008 by Rivka Pomerantz, BSN, RN, IBCLC. It seeks to provide a forum to discuss professional issues related to Orthodox Jewish nurses and arrange social and educational events. We strive to meet the needs of our members, promote professionalism and career advancement, and be a voice for Orthodox Jewish nurses across the world.

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Editor's Note

Dear Members,

Jews are a fairly genetically isolated population. Due to the internal injunction against intermarriage and the external pressures of anti-semitism, the Jewish population has remained somewhat segregated from a genetic standpoint. These circumstances provide a remarkable opportunity for the study of genetic diseases, as well as the implementation of public health genetic initiatives and advances in the treatment of genetic disorders [1]. The Tay Sachs carrier screening program, which has reduced the disease by 90% in the Ashkenazi population [1], is widely considered a model for how a successful genetic screening program can operate. Gaucher disease, also endemic to the Ashkenazi population, was the first disease in which enzyme-replacement therapy was successfully utilized [1]. Even among the non-Mendelian diseases, such as Parkinson's disease and Crohn's disease, where multiple genes and the environment play a part in disease expression, the Jewish genetic tapestry provides a rich environment to study the genetic underpinnings of these diseases and to develop genetically driven treatments. It is no surprise then, that as Orthodox Jews, we have an ingrained familiarity and intimacy with our genes and genome.

In our role as nurses, we are uniquely positioned to bridge the gap between genetics research and successful adoption into practice [2]. Interestingly, it was not until 1998 that genetics was first recognized as a nursing specialty, and it was only in June 2008 that the American Association of Colleges of Nursing developed "The Essentials of Genetic and Genomic Nursing: Competencies, Curricular Guidelines, and Outcome Indicators" to integrate genetics and genomics education into its list of essential education for baccalaureate prepared professional nurses [3]. Because of the delayed entree the nursing profession has taken into the field of genetics and genomics, nurses may have inadequate understanding of the relevance genetics plays in nursing and healthcare, and may be unable to apply it to their nursing practice. Yet nurses need to be competent in obtaining thorough family histories to identify red flags and markers of genetic disorders, recognize the potential for genomics-influenced drug reactions, clearly explain the results of genetic tests, and to know when to refer patients to genetic specialists [2,4].

The medical world is swiftly moving towards personalized medicine in which an individual's genetic and genomic information can help determine his susceptibility to diseases, guide screening decisions, choose treatments tailored to maximize successful outcomes, and avoid adverse drug reactions. Nurses need to be at the forefront of this changing healthcare arena. Our Jewish heritage gives us the background and our nursing practice provides the impetus. Join me in this exploration of genes as they interplay with medicine, history, and the future.

Best,

Chaya Milikowsky, MSN, AG/ACNP-BC

Editor-in-Chief, The OJNA Journal

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CANCER

THIS ISSUE AT A GLANCE:

[T]HE ABILITY TO ENGINEER VACCINES THAT INDUCE A GREATER PERCENTAGE OF ROBUST IMMUNE RESPONSE WHILE **SIMULTANEOUSLY REDUCING THE RISK OF ADVERSE EVENTS** IS AN EXCITING PROSPECT.

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However, just because **WE CAN** make "designer babies" does not mean that **WE SHOULD,** ethically or halachically.

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More than **46%** of Kohanim can trace their paternal lineage back to a single male from over **3,000** years ago.

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A ***founder mutation*** (or effect or variant) occurs when there is a genetic alteration caused by an ancestor carrier of an altered gene in an isolated group"

To date, there are more than **40 genetic, endocrine**, and metabolic disorders that are tested for in the NBS program"

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Gene Therapy may one day **be the cure** for TSD and similar diseases page 9

IN **22 STATES,** NPS HAVE FULL PRESCRIPTIVE AND PRACTICE AUTHORITY TO THE FULL EXTENT OF THEIR LICENSE WITHOUT COLLABORATION WITH ANY OTHER PROVIDER

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Back then, I wished that there was ***someone to guide me*** and who perhaps may have had experiences similar to mine. page 25

in certain ethnic groups, such as **Ashkenazi Jews,** mutations in the BRCA1 and BRCA2 cancer susceptibility genes are more prevalent page 11

...identified four regions on the genome that appear to be highly influential in determining left-handedness

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IT'S AN ETHICAL DILEMMA, BUT FOR NOW, ***I WOULD RATHER NOT KNOW.***

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Genetic Disorders Affecting the Ashkenazi Population

Tobi Ash, MBA, BSN, RN

Genes

What makes you, you? Your genes. Every human has a unique genetic code made of genes. Genes are the basic physical and functional unit of heredity and are made of DNA. Each gene ranges from a few hundred DNA bases to more than 2 million. A human being has between 20,000 to 25,000 genes. Each person inherits two copies of each gene, one copy from the mother and the other from the father. Most of our genes are the same; less than one percent of genes differ between people. These differing components are known as alleles. Alleles are forms of the same gene but with small differences in their DNA bases, and alleles are what make each one of us unique. One's genotype is the internal, inherited genetic code inside all living organisms and is related to all that is physical, functional or behavioral. A phenotype is the outside, physical manifestation of those genes. Phenotype examples include skin, eye, and hair color. [1,2]

What is a genetic disease?

Genetic diseases are caused by an abnormality in a person's genetic makeup. This abnormality can be due to a tiny aberration in a single base in the DNA, or due to a chromosomal addition or subtraction of either a single or set of chromosomes. These diseases can be inherited from parents, acquired mutations in a pre-existing gene, a random occurrence, or environmentally caused. Inherited genetic disorders include single gene disorders or those that are multifactorial. They may arise from the chromosomes or mitochondria. [3]

There are thousands of disorders related to single gene inheritance. Also known as Mendelian or monogenetic inheritance, single gene inheritance occurs when a mutation or change happens in the DNA sequence of a single gene. Single gene inheritance disorders can be autosomal dominant, autosomal recessive, or x-linked. Autosomal dominant disorders occur when one copy of a defective gene is passed from either parent to the child. Individuals with autosomal recessive disorders inherit two copies of a defective gene, one from each parent. X-linked disorders are those where defective genes are passed on from the mother to her child. Examples of single-gene diseases include Cystic Fibrosis, Fragile X Syndrome, and Alpha and Beta-thalassemias. [3]

Multifactorial genetic disorders, also known as complex or polygenic inheritance, have several causes. Most disorders or diseases are due to mutations in multiple genes and environmental factors. Examples of multifactorial diseases include heart disease, breast cancer, diabetes, and Alzheimer's Disease. [3]

Chromosomal Abnormalities

A chromosomal abnormality occurs when the structure or the number of chromosomes is atypical, or where parts of the chromosomes are exchanged (translocated). Examples of chromosomal abnormalities include Down syndrome (three copies of chromosome 21; also known as trisomy 21), Turner syndrome (45 chromosomes, missing one X), and Klinefelter syndrome (47 chromosomes and affected males have an extra X chromosome). [3]

Mitochondrial Inheritance

Mitochondrial disorders occur when the non-nuclear DNA of the mitochondria develops mutations. Examples of mitochondrial disorders include myoclonic epilepsy and Leber's hereditary optic atrophy. [3]

Medical Genetic History of Jews

Jews are a religious and ethnic group who originated in the Middle East more than 4,000 years ago. Although Jews originated in the Middle East, the historical exiles of Jews from their homeland meant that almost all Jewish populations were widely dispersed. The study of population genetics investigated the origins of these disparate populations to determine if there was a common genetic heritage. Multiple studies of autosomal DNA show that the genetics of Ashkenazi, Sephardi, and Mizrachi Jews share ancestry despite the thousands of years of separation [4,5].

How did the Jews keep it, so to speak, "in the family" if they lived in various non-Jewish communities? Interfaith marriage in Judaism (intermarriage) has been highly discouraged. In Devarim (Deuteronomy 7:3) it states: "You shall not intermarry with them; you shall not give your daughter to his son, and you shall not take his daughter for your son" [6]. As a result, Jewish law and custom prohibited marriage between a Jew and a non-Jew. It appears most Jews were careful to only marry other Jews in the subsequent millenia.

The Talmud discusses hereditary diseases including hemophilia, epilepsy, and leprosy [7]. While there have been some in Jewish communities that were fearful of genetic testing due to concerns about medical racism and the threat of eugenics, the overall goal of identifying people at risk of either being born with or developing a genetic disease in the future propelled modern genetic testing programs [8].

There are approximately 10 million Ashkenazi Jews in the world today with close to 3 million living in Israel. Ashkenazi Jews descend from a small number of founders with a strong tradition of marriage within their own community (endogamy). This custom of faith created a much more homogenous genetic background as compared to other group and thus there is a high incidence of rare genetic diseases within the Ashkenazi Jewish population as opposed to the larger population. The origin of currently investigated mutations can be traced back to the time period between the 9th and 14th centuries. The high frequency of specific genetic disorders occurring in the Ashkenazi Jewish population leads us to assume that a "founder" chromosome, carrying the disease allele, was in a very small group (estimated to approximately 100 people). [9-11]

When a small group of individuals isolates themselves from a larger group, this new isolated group will resemble only the individuals in this distinct population. A founder mutation (or effect or variant) occurs when there is a genetic

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Chromosomes are located in the nucleus of the cell and made up of DNA (genetic material) and protein. A human cell contains 23 pairs of chromosomes with one half inherited from the mother and one from the father.

Mitochondria are the rod or round organelles involved in cellular respiration. Each has between 5-10 pieces of DNA. Egg cells keep their mitochondria during fertilization. This type of DNA is always inherited from the mother.

Each person has paired genes: one from the father and the other from the mother. Inheriting a genetic disease or condition depends on the type of chromosome affected (sex or non-sex chromosome). An autosomal disorder is when there is an abnormal gene on one of the first 22 (non-sex) chromosomes. The trait may be dominant or recessive. [13]

A carrier is a person who has a change in only one gene. Carriers are healthy people who are at risk of passing this mutation on to their children. Carrier frequency tells us how often a mutated gene is present in a specific group. If both parents are carriers of a defective or mutated gene, there is a 25% chance they will give birth to an affected child, a 50% chance they will give birth to a carrier (like themselves), and a 25% chance of giving birth to a child who is neither affected nor a carrier. [14]

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alteration caused by an ancestor carrier of an altered gene in an isolated group. This is known as the founder effect. [12]

Genetic Diseases in the Ashkenazi Jewish Community

Many genetic disorders affecting the Ashkenazi Jewish community are lysosomal or non-lysosomal storage disorders. Lysosomes are cell organelles and contain enzymes that metabolize lipids, glycoproteins, or mucopolysaccharides. They function as a recycling center. If any of the enzymes are missing or defective due to a genetic mutation, these molecules continue to accumulate inside the cell, eventually destroying it. These disorders can be caused by recessive or dominant genes. Lysosomal storage diseases that affect the Ashkenazi Jewish population include Tay Sachs (recessive), Gauchers (recessive), Niemann-Pick (recessive), and Mucolipidosis (recessive). Non-Lysosomal storage diseases affecting the Ashkenazi Jewish populations include Bloom Syndrome (recessive), Fanconi Anemia Type C (recessive), Canavan (recessive), and Familial Dysautonomia (recessive). [14,15]

Autosomal Recessive Diseases

An individual must inherit two mutations of the same disease for a genetic recessive disease to occur. The following diseases are especially common in Ashkenazi Jews due to high carrier frequency*.

Gaucher Disease (1 in 15)

Gaucher (pronounced go-shay) Disease can be classified into three different types and occur due to a deficiency of the glucocerebrosidase (GCase) enzyme. Ashkenazi Jews most commonly present with Type 1 Gaucher Disease. Features include an enlarged, overactive, and painful spleen, low white blood cell count, and anemia. Bone deterioration causing disability and pain may also be present. Symptoms can appear anytime from childhood to adulthood and progression of the disease is variable. Enzyme replacement therapy can help prevent or lessen the severity of this disease. Partial or full splenectomy, blood transfusions, joint replacement, and FDA approved *eligustat tartrate* are among the treatments for Gaucher Disease. Individuals who present with Gaucher Disease Type 2 and 3 may suffer from profound brain damage, for which there is currently no treatment. [16]

Cystic Fibrosis (1 in 24)

Cystic Fibrosis (CF) affects multiple body systems as an accumulation of thick, sticky mucus that damages lungs and other internal organs. This results in chronic lung infections, wheezing, year-round allergies, and progressive decrease in lung function. Gastrointestinal symptoms include recurrent pancreatitis, foul, greasy bowel movements, chronic constipation, and diabetic-like symptoms such as constant thirst and urination. Patients may sweat excessively and their sweat may "taste" very salty. Due to impaired absorption, patients with CF have poor growth. Chronic infections, declining lung function, and poor nutritional absorption lead to a shortened lifespan. The carrier test has a 97% detection rate for Ashkenazi Jews. [17]

Tay-Sachs Disease (1 in 30)

Tay-Sachs is a severe neurodegenerative disease with deterioration of neurons in the brain and spinal cord due to a lack of the hexosaminidase (Hex A) enzyme. An infant with Tay-Sachs develops normally until four to six months of age, and then the central nervous system (CNS) begins to degenerate. The most common first symptom, prior to CNS deterioration, is a cherry-red spot on the back of the eye. Early symptoms seen in these infants include mild muscle weakness, twitching or myoclonic jerks, and an exaggerated startle response. The baby then develops seizures, spasticity, loss of all motor skills, deafness, blindness, and non-responsiveness with death at about age four or five. There is currently no cure for Tay-Sachs. [18]

Familial Dysautonomia (1 in 35)

Familial Dystautonomia (FD) causes malfunctions in the nerves responsible for most involuntary body functions of the autonomic nervous system. This affects the body's stress response, blood pressure, regulation of body temperature, and swallowing. Symptoms include poor weight gain, indifference to pain, gastrointestinal issues, and the inability to produce tears when crying. Prior to 1960, 50% of affected individuals died before age five. People with this disease have a shortened lifespan. [19]

Spinal Muscular Atrophy (1 in 76 Ashkenazi; 1 in 34 Sephardi)

Spinal Muscular Atrophy (SMA) is characterized by loss of control of muscle movement with reduction of motor neurons in the brain and spinal cord. Physical and speech therapy, assistive devices to aid in functional independence, and proper nutrition are some of the treatments used for patients with SMA. In December 2016, the Food and Drug Administration (FDA) approved nusinersen (Spinraza), a drug injected into the fluid surrounding the spinal cord as a treatment for children and adults with SMA. Infants and children respond best to this treatment as compared to adults. In May 2019, the FDA approved a gene therapy called Zolgensma (onasemnogene abeparovecxioi) for children under age two with infantile SMA. This gene therapy delivers a virus to specific motor neurons to improve muscle movement, muscle function, and patient survival. The cost for Zolgensma is $2 million, and this drug received tremendous media attention when a young Jewish baby girl with SMA crowd-funded $2.2 million from 23,000 donors in under five days. The baby received the treatment merely days before turning two years old. Besides for this new genetic therapy, there currently is no cure for SMA. [20,21]

Canavan Disease (1 in 50)

Similar to Tay Sachs, Canavan Disease is a progressive, non-curable, neurological disorder in which oligodendrocytes, the cells responsible for making myelin sheaths to cover the axon, cannot complete their task due a mutation in the enzyme aspartoacylase. The brain degenerates into spongy tissue. Symptoms usually begin the first three to six months of the infant's life, and signs and symptoms include an abnormally large and poorly controlled head, lack of motor development, weak or stiff muscle tone, feeding difficulties, blindness, deafness, and paralysis. Death usually occurs at age four to five years. There is no cure. [22]

Fanconi Anemia – Type C (1 in 82)

Fanconi anemia affects the bone marrow, decreasing the production of white cells, red blood cells, and platelets. This condition is diagnosed in childhood rather than in infancy. Symptoms include abnormal heart, lungs, and gastrointestinal tract, characteristic café au lait spots, vitiligo, deafness, short stature, improperly formed kidneys, and intellectual and learning disabilities. Scoliosis, missing, extra, or misshapen bones in the arms and hands are present in this disease. Fanconi Anemia is associated with a predisposition to leukemia and other cancers. There is no cure; treatment is limited to symptomatic care. [23]

Mucolipidosis IV (1 in 92)

Mucolipidosis is characterized by an accumulation of abnormal amounts of lipids and carbohydrates in cells, damaging the cells. There are four types of Mucolipidosis, and in type IV, manifestations of the disease can begin in early infancy. Symptoms include a cloudy cornea and profound motor and developmental delays as disease progression causes a crippling of the CNS. Most children with this disease never walk, and some are severely developmentally delayed by age three. Treatments include supportive care and addressing specific symptoms. There currently is no cure. [24]

Niemann-Pick Disease – Type A (1 in 98)

Niemann-Pick is a progressive neurodegenerative disease. It is caused by a buildup of lipids in the brain, spleen, liver, lungs, and bone marrow

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and is due to a deficiency in the enzyme sphingomyelinase. This enzyme deficiency allows for the continual toxic build-up of sphingomyelin, a fatty substance contained in every cell of the body. There are several variations of Niemann-Pick Disease; Type A is the one most frequently found among Ashkenazi Jews. Death occurs between 18 months and three years of age. At age six months, infants will have recurrent vomiting, lack of muscle control, enlarged spleens and livers, swollen lymph nodes, and profound brain damage. Type B and Type C are less common in Jewish populations. Both occur past infancy. There is no cure or treatment for Type A. For Type B, there have been some treatment attempts such as bone marrow transplants, enzyme, and gene therapy. [25]

Bloom Syndrome (1 in 117)

Blood Syndrome is characterized by short stature, and those affected record height and weight in the third percentile starting from birth. These individuals rarely reach a height of five feet tall during adulthood. Other signs and symptoms include reddened patches on the nose, cheeks, and skin, telangiectases (clusters of enlarged blood vessels) in the eyes or on the skin, as well as hypo or hyperpigmentation. This disorder is rare in the general population. Bloom Syndrome greatly increases the risk of any cancer, early onset cancers, and the development of more than one type of cancer. There is no cure: treatment is limited to symptomatic care. [26]

Autosomal Dominant Diseases

An autosomal dominant disease occurs when only one abnormal gene from one parent can cause disease even though the matching gene from the other parent is normal. In this situation, the abnormal gene dominates over the healthy gene. A parent with an autosomal dominant disease has a 50% chance of giving birth to a child who will have this disease. This is true for each pregnancy. A baby who does not inherit the abnormal gene will not develop or be able to pass on the disease. This disease can also happen in a child when neither parent has the abnormal gene. If the child is diagnosed with an autosomal dominant disease, the parents should be tested. [27]

There are autosomal dominant diseases which are more prevalent in the Ashkenazi Jewish population. Some of the more common ones are:

Breast Cancer (BRCA1/2 incidence 1 in 40)

The BRCA genetic mutation increases the risk for melanoma, breast (female and male), ovarian, prostate, and pancreatic cancers in Ashkenazi Jews at more than 10 times the rate than the general population. There are three specific mutations (two in the BRCA1 gene and one in the BRCA2 gene) seen in the Ashkenazi Jewish population. Jewish men can also inherit BRCA2, and to a lesser extent, BRCA1, which increases their risk for breast and prostate cancer. Both men and women are at increased risk for pancreatic cancer. [28]

Gastro-Intestinal Cancers

There are two genetic mutations in Ashkenazi Jews linked to gastrointestinal cancers. One is known as APC (Adenomatous Polyposis Coli), which is found in about 6% of Ashkenazi Jews, increases the risk of colon cancer, and is double the risk of the general population. The second genetic mutations is HNPCC (Hereditary Nonpolyposis Colorectal Cancer or Lynch Syndrome), and this raises the risk of colon cancer at a much younger age (below 40 years old). The HNPCC mutation is also associated with other gastrointestinal cancers, including stomach, small intestine, bile duct, and pancreatic cancers. In addition, this mutation raises the risk of reproductive cancers and brain cancer. [29]

Sephardi Genetic Diseases

Sephardi Jews have their own set of distinct genetic diseases based on their country of origin. Because Sephardic Jews come from a more complex and genetically diverse background, there are fewer genetic diseases common to all Sephardi Jews.

Beta-Thalassemia (1 in 30 carries/ 1 in 3,600 develops the disease)

Beta-Thalassemia reduces the amount of hemoglobin found in the blood. The earlier the disease manifests, the more severe the condition. Symptoms of early onset Thalassemia include anemia, weakness, jaundice, and failure to thrive. Patients may require multiple blood transfusions. Later onset of this disease has a milder manifestation with moderate anemia and bone abnormalities. [30]

Familial Mediterranean Fever (1 in 14 Sephardic, 1 in 15 Armenian and Turkish descent)

This disease affects North African (Moroccan, Tunisian, Libyan, Egyptian, Algerian) and Iraqi Jews, as well as those of Armenian and Turkish heritage. The disease is characterized by recurring 12 to 72-hour bouts of fever with painful inflammation in the chest, joints, or abdomen. This usually begins between ages five and 15. Prior to the attack, some patients have a prodrome, which is an uncomfortable feeling in the areas that will be become inflamed in the attack. The attacks can vary in length of time and in severity, and the timing between attacks can vary as well. Without treatment to prevent attacks, protein deposits can build up in the body, especially in the kidneys, leading to kidney failure. Standard treatment is Colchicine, and other treatments include medications that block interleukin-1 including canakinumab (Ilaris), rilonacept (Arcalyst) and anakinra (Kineret). [31,32]

Genetic Testing in Jewish Populations

Chromosomes were identified in the late 1800s and were linked to genetic diseases in the early 1900s. In the 1950s, scientists developed genetic testing for Down Syndrome, Duchenne muscular dystrophy, and cystic fibrosis. In the

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1960s, genetic testing for diseases such as phenylketonuria (PKU) was used to determine if a condition was a genetic disorder. Testing was done on newborn infants. Currently, there are more than 500 laboratories that perform genetic testing for more than 2,000 genetic conditions. [33]

Genetic testing is divided into the following categories:

1. Diagnostic: identifies the condition
2. Predictive (pre-symptomatic): identifies genetic variations that increase the risk of developing a genetic disease
3. Carrier: identifies genetics that can be passed on to the individual's children; either as a carrier or develop the disease
4. Prenatal: done during pregnancy to identify disease in the fetus
5. Preimplantation: determines if an embryo carries genetic disease, done prior to in vitro fertilization
6. Newborn: tests infants for specific diseases within the first few days of birth

Some of these tests can be purchased or done directly by the consumer. Most require a medical professional to order and interpret. [33]

The American College of Obstetricians and Gynecologists (ACOG) recommends pregnant Ashkenazi individuals be offered screening as routine obstetrical care for diseases such as Tay-Sachs disease, Canavan disease, Cystic Fibrosis, and Familial dysautonomia. Some advocate for additional testing for Bloom syndrome, Fanconia anemia, Gaucher, Mucolipidosis, Niemann-Pick, Maple syrup urine disease, Usher syndrome, Joubert syndrome, Glycogen storage disease, and Familial hyperinsulinism. [34]

One of the first genetic tests, developed in 1970, was used to identify carriers for Tay-Sachs disease. This had a tremendous impact on the incidence of this disease with a decrease in the amount of cases seen in the Ashkenazi Jewish community. [35,36]

Dor Yeshorim (Upright Generation) was started by Rabbi Joseph Ekstein from Brooklyn, New York, in 1983. This program does anonymous genetic screening of individuals prior to marriage to determine their genetic status. Testing is usually done in large groups, such as high schools or yeshiva. The results are entered into a database, and identified only with a unique PIN number that is given to the tested individual. Most couples check their compatibility early during a dating relationship. If they are considering marriage, they call Dor Yeshorim and give their PIN numbers, and the organization checks whether they are genetically compatible. If both individuals are carriers for a specific disease, the individuals are told the match is incompatible. If neither are carriers, or only one is a carrier, the match can proceed. Callers are not told whether members are carriers to prevent stigmatization of the individual or their family. By avoiding marriage between two carriers, the incidence of autonomous recessive disorders decreased dramatically. [37]

This organization only screens for recessive genetic disorders. They currently test for Tay-Sachs, Familial dysautonomia, Cystic Fibrosis, Canavan disease, Glycogen storage disease type 1, Fanconi anemia type C, Bloom Syndrome, Niemann-Pick disease, Mucolipidosis type IV, and Gaucher (upon request). Dor Yeshorim does not screen for dominant gene mutations, even though these do occur in the Ashkenazi Jewish community. [37]

JScreen, a new non-profit organization, tests for up to 226 (as of 2017) genetic conditions. While most genetic testing is done in a large community setting (Dor Yeshorim) or in a doctor's office, JScreen is done in the privacy of an individual's own home. They screen for over 200 recessive genetic diseases that are common in Ashkenazi, Sephardi, and Mizrachi populations. Similar to Dor Yeshorim, JScreen only offers tests for future reproductive recessive genetic disorders. JScreen has recently started a pilot BRCA screening project, called Peach, in the Atlanta area for Ashkenazi Jewish individuals. [38]

Ideally, carrier screening, and if necessary, counseling, should be done prior to getting pregnant. Dor Yeshorim, JScreen, and ACOG recommend this to allow individuals and couples to learn about their reproductive risks. If an individual is found to be a carrier for a specific genetic condition (whether recessive or dominant), they should inform their family at risk of carrying the same mutation to assess their own risk and do carrier screening. Screening is not mandatory, and an individual has the ability to decline any genetic test. If both members of a couple are found to be carriers, they should be offered genetic counseling. If one of the partners is a carrier, the other partner should be offered genetic testing to determine potential reproductive outcomes. [34,37,38]

Web Resources for Jewish Genetic Diseases:

Jewish Genetic Diseases
https://www.jewishgeneticdiseases.org/jewish-genetic-diseases/

JScreen
www.jscreen.org

Gaucher
www.Gaucherdisease.org

*All carrier frequency information was retrieved from Mt. Sinai, NY [39]

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RESEARCH RECAP

OJNA Journal Staff

Vaccinomics and Adversomics

Vaccines are undoubtedly one of the most important and effective life-saving interventions of the 20th century. Yet fear of adverse events, whether real or imagined, is increasingly becoming the greatest impediment toward vaccine acceptance, leading to vaccine hesitancy and refusal. Vaccines are remarkably safe, held to strict safety standards, and have risk profiles lower than those of most drugs. However, the vaccine ideal, wherein a protective immune response is generated in every vaccinated patient without adverse effects, does not exist. This is due in part to heterogeneity in the very complex human immune response, much of which is mediated by an individual's genes. It is well documented that women develop a better humoral response to vaccines, but are also more likely to suffer from adverse effects [1]. Immunosenescence, the waning of immune response with age, is thought to be under genetic guidance [5]. Immunosuppressed individuals occasionally demonstrate weaker or rapidly waning immune responses to vaccines [2]. Racial and ethnic groups, and sub-populations with genetic polymorphisms are others whose immune systems may not respond in the desired fashion to generic vaccines [2].

"Vaccinomics" is a term coined by Dr. Gregory Poland in 2007. It refers to the study of immune responses to vaccines in which host genes, epigenetics, the microbiome, complement function, co-infections, and other factors are taken into account with the aim that vaccine-induced immunity be understood, predicted, and then applied to vaccine development [3].

"Adversomics" is a related new field in which vaccine adverse reactions are studied using immunogenomics to understand the genetic underpinnings of untoward immune responses, auto-immune reactions, inadequate responses, or vaccine failures [4]. These maladaptive responses to a vaccine are likely a combination of yet unidentified factors on top of personal genetic characteristics, vaccine antigen characteristics, adjuvants, and dosage. Understanding how these factors interact can help predict those most susceptible to vaccine reactions and safely guide alternatives, as well as to develop vaccines that avoid the identified reactions. It can also help determine those who may not develop a robust immune response to the standard vaccine regimen and offer strategies for optimization, such as utilizing individualized adjuvants to stimulate an increased immune response. Some of the technologies involved in these burgeoning fields include flow cytometry, high throughput DNA sequencing, proteomics, metabolomics, and mass spectrometry [2].

In spite of the public push towards personalized medicine, barriers remain towards rapid advancement of vaccinomics and adversomics. Adverse events (AE) are rare, and it can be difficult to determine causality. Even if an AE appears to be causally related, it may not be the actual cause of the event. For example, the desired immune response generated by the vaccine may unmask an innate genetic deficit in some children, such as a tendency towards epilepsy [4]. Furthermore, as the human genome is enormous, scientists still need to amass a larger compilation of genotype/phenotype data so that specific SNPs that are associated with specific adverse reactions can be identified. This endeavor will also require the development of biomarkers to help stratify patients based on potential risk. [5]

These fields remain in their infancy but hold promise. In today's society of increasing skepticism and concern about vaccine safety, the ability to engineer vaccines that induce a greater percentage of robust immune response while simultaneously reducing the risk of adverse events is an exciting prospect.

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Candida Auris

A new *Candida* strain has been appearing with increasing frequency in hospitals and healthcare facilities around the world. This *Candida* strain was first recognized in 2009 after being isolated from the ear of a patient in Japan, hence the name *Candida* ***auris.*** It has now been identified in 23 countries across the world and in 10 states within the United States. To date, four distinct "clades", or strains, of the yeast have been identified via genetic sequencing. These four strains appear to have emerged in four different geographic regions independently and simultaneously. How and why this occurred is unknown. Theories include the increasing use of prophylactic antimicrobial and antifungal medications, changes in the environment, and the possibility of animal reservoirs.

Candida auris is unusually concerning because it is the first multidrug resistant (MDR) yeast and is associated with a high mortality rate. Currently, there are three main classes of antifungal medications: triazoles, amphotericin B, and echinocandins. While slight differences exist between the four clades, *Candida auris* is usually resistant to fluconazole, often resistant to amphotericin B, and occasionally resistant to echinocandins. Unlike most *Candida* infections, *Candida auris* has the ability to spread between patients. Patients can be colonized with *Candida auris* without disease for long periods of time. This is concerning because it allows for transmission to others and also can lead to active invasive infection following a precipitating event.

A further concerning feature about *Candida auris* is that it is often undetected or misdetected. Most hospitals do not seek to clarify *Candida* infection to the species level, and even in those that do, *Candida auris* might easily be misidentified as other *Candida* species when run through conventional microbiological testing equipment. The use of polymerase chain reaction (PCR) testing is being studied as a potential tool for rapid identification of *Candida auris*.

A final worrisome feature of *Candida auris* is its association with high mortality. Blood stream infections related to *Candida auris* has a mortality rate of 30-60%. However, it is unclear whether that mortality is directly related to the candidemia itself, or whether it's a reflection of the underlying morbidity of patients who develop the infection, as invasive *Candida auris* is more often found in patients with multiple comorbidities and high degrees of healthcare exposure.

Public health departments in the United States and around the world are developing policies and bundles towards the detection and management of this emerging "superbug". Because there is so much yet unknown about *Candida auris,* infection control strategies are extrapolated from those of other MDR organisms, such as methicillin-resistant Staphylococcus aureus (MRSA), carbapenem-resistant Enterobacteriaceae (CRE), and Clostridium difficile (C-diff). Recommendations beyond standard precautions include isolation for those with both infection and colonization, active surveillance and screening of contacts if a case is reported, terminal cleaning, and decolonization. Unfortunately, typically utilized disinfectants, such as chlorhexidine and ultraviolet light, appear less effective against *Candida auris* than against MDR bacteria.

As *Candida auris* becomes more prevalent universally, joint efforts by international players and healthcare organizations will become important to develop better techniques for identification, prevention, and treatment of this newly recognized pathogen. In addition to concerns about the morbidity and mortality associated with this organism, *Candida auris* also challenges our assumptions about fungal transmission and drug resistance patterns. It is a reminder that we cannot become complacent in the battle against infectious diseases.

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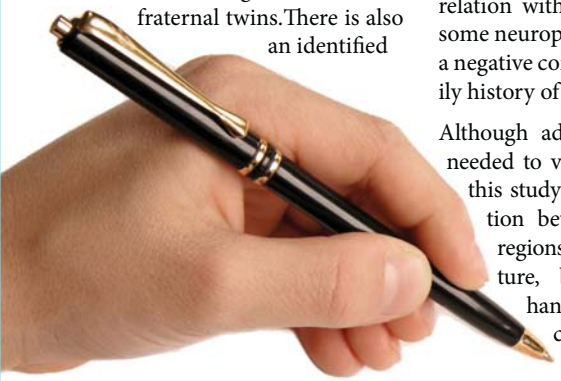
Handedness

The trait of handedness, or the tendency to use one hand more naturally than the other, is determined in utero, becomes increasingly evident in childhood, and remains static throughout one's life. This trait is related to brain asymmetry, as the right side of the brain controls the left side of the body and vice versa. A preference for one hand reflects the activity occurring in the different hemispheres of the brain. The language centers of the brain are primarily situated in the brain's left hemisphere and it has been assumed that right-handedness, which accounts for approximately 90% of the population, is related to the left lateralization of language centers in humans.

It has been long recognized that there is some genetic component at least partially associated with the trait of handedness. Left-handedness seems to run in families, and studies of twins have shown that the trait is more common among identical than fraternal twins.There is also an identified



correlation between left-handedness and schizophrenia, with 40% of schizophrenics being left-handed as opposed to 10% in the general population. The extent to which genetics appears to play a part has been approximated at 25% with the environment and other factors exerting a larger influence. Until recently, no specific genes have been identified as contributing to handedness, and studies of brain neuroanatomy have not been conclusive, with no structural differences found in the brains of righties and lefties.

A recent paper by Wiberg, et al. (2019) of the University of Oxford, published in Brain, A Journal of Neurology, reports to have identified four regions on the genome that appear to be highly influential in determining left-handedness. This was found through genome-wide analysis of 400,000 British individuals and comparing it to self-reports of handedness (as well as many other health and lifestyle parameters). Three of these loci are associated with the development of cellular microtubules, the organelles that give structure to the brain cells. The paper also looked at fMRI imaging from a subset of 9,000 of these individuals and found an association between lefties and stronger right-left brain connectivity, specifically increased structural networks in the white matter tracts linking language regions of both brain hemispheres. In addition, the study analyzed the suspected correlation between handedness and some neuropsychiatric disorders, finding a positive correlation with schizophrenia and some neuropsychiatric traits, and a negative correlation with a family history of Parkinson's disease.

Although additional studies are needed to validate these results, this study points to a connection between specific gene regions, neuron architecture, brain lateralization, handedness, neuropsychiatric phenotypes, and language function. This suggests a common genetic influence on handedness and neuropsychiatric phenotypes, and indicates that the proteins of the cytoskeleton play a likely role in neuron development and migration. It also substantiates previously recognized associations between left-handedness and more symmetrical language function in the brain. Whether left-handedness provides an actual verbal advantage was not investigated in this study.

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Investigational Gene Therapy for Tay-Sachs Disease

Tay Sachs disease (TSD) is a progressive neurodegenerative disorder with a median lifespan of approximately 3-4 years. It belongs to the family of lysosomal storage diseases, in which an enzyme deficiency leads to the body's inability to remove or reuse waste-products in the cell. This causes a build-up of large molecules within neuron lysosomes that ultimately leads to cell destruction. In the case of TSD, defects in the enzyme Hexosaminidase A (HexA) cause the build-up of the lipid GM2 ganglioside within the cells of the central nervous system. Clinically, children born with TSD develop normally until about six months of age, at which point they cease meeting developmental milestones. They subsequently lose muscle function and cognitive ability, endure seizures, and eventually lose the ability to move or breathe. TSD is an autosomal recessive disorder, meaning both parents must be carriers of the disease to have a child with the disease. In such a case, there is a 25% chance of having an affected child with each pregnancy. [1,2]

In the general population, about 1 in 250 people is a carrier of the Tay Sachs gene. Within the Ashkenazi Jewish population, the likelihood of being a carrier is 1 in 27. Those of Cajun, French-Canadian, and Irish descent also have an increased likelihood of being a TSD carrier, with rates between 1 in 27 to 1 in 50. Because TSD is often thought of as a "Jewish disease," providers may be less likely to test for and diagnose a non-Jewish child presenting with neurodegenerative symptoms. [2]

In October of 2019, a preliminary report announced the investigational administration of gene therapy AXO-AAV-GM2 to two children with TSD. The first child is 2.5 years old with advanced disease. He remains clinically stable with biochemical evidence of improved HexA activity, but has not had recognizable clinical improvement. The second child, significantly younger at just six months old, was given the gene therapy prior to the onset of severe symptoms, and to date has shown stabilization of the disease without further progression. MRI imaging on this child shows normal anatomy and increased myelination as compared to the demyelination and cortical atrophy usually seen in TSD patients at this point. [1,3]

Research and development of this potential gene therapy for TSD has been carried out by the University of Massachusetts Medical School and Auburn University's college of veterinary medicine. They use the viral vector adeno-association virus (AAV) to deliver a functional copy of HexA to the brain and spinal cord. When the vector enters the neurons, it releases the HexA gene which then goes on to produce the HexA enzyme. The working HexA enzyme is secreted and distributed throughout the brain. [2]

This therapy was first studied in cats and then tested in Jacob sheep, a breed of sheep that have a naturally occurring variant of TSD. Positive results in these animal studies encouraged an expanded access, or "compassionate use," trial of AXO-AAV-GM2 in two children. Axovant, a clinical-stage gene therapy company, has now licensed the program and they are planning a Phase 2 trial. [2,3]

While this gene therapy is far from a magic elixir, it encourages hope that gene therapy may one day be the cure for TSD and similar diseases.

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OJNA LEADERSHIP UPDATE:

The board members of OJNA continue to work on organizational growth and development, team building, strengthening OJNA committees, and growing our reach across the United States, Canada, and Israel. The organization continues to grow in membership, expand and improve member resources and services, and host multiple social and educational events.

Team Building

This past Summer, the board members attended a team building event and got to know our newest board member, Toby Bressler, on a more personal level. The board members enjoyed good food and had a great time axe throwing in Brooklyn, New York!

Career Building

OJNA's New Grad Committee held a career event on August 19, 2019 at Morgan Stanley Children's Hospital of New York Presbyterian. Participants learned from Rabbi Mordechai Kruger, MS, JCTC how to prepare their resume and cover letter and ensure they personally stand out from other applicants during the interview process. Information was also shared about interview follow-up and correspondence. Rabbi Kruger's presentation was extremely informative and entertaining! We thank Morgan Stanley Children's Hospital of New York Presbyterian for their support of this event.

Community Networking

OJNA was represented at Achiezer's Jewish Healthcare Conference and Expo on September 15, 2019. This event educated and empowered attendees about how to best care for themselves and others. It addressed the needs of caregivers and proactive adults seeking to maintain their own health and plan for their retirement years. At the OJNA booth, our nurses networked with larger organizations and spread information about OJNA's mission and membership benefits.

Continuing Education

OJNA partnered with Nishmat in offering a webinar series on Women's Health & Jewish Law. This webinar series started in October 2019 and extends over a 14-week period. While OJNA did not review or endorse the materials, OJNA felt is was important to offer this learning opportunity to its members. Paying members of OJNA received a significant discount for this educational series, and we are grateful to Nishmat for providing the opportunity to our group.

Networking Events

OJNA held free networking events for nurses in Pittsburgh, Los Angeles, Chicago, and Elizabeth, New Jersey. Attendees enjoyed meeting one another, sharing best tips for career and work/life balance success, and heard from inspiring speakers. Upcoming events in Florida and Baltimore are being planned. To host a networking event in your area, contact us via our website and we will be glad to assist with logistics, publicity, and finances!

Organizational Development

OJNA elections for treasurer and secretary were held on December 1, 2019. OJNA members with active, paid membership for at least six consecutive months prior to elections were eligible to vote. No applications were received for new candidates. Mara McCrossin will remain as OJNA treasurer and Chaya Milikowsky will remain as OJNA secretary for the next two years. The next elections will be held in December 2021.

Professional Development

In November 2019, OJNA received Institutional Review Board (IRB) approval for its successful new graduate mentorship program. This is an exciting professional accomplishment, and we look forward to collecting data for our very first OJNA Nursing Research Study!

OJNA is excited to report that it has become an organizational affiliate of the American Nurses Association. Official press release can be viewed on page 26.

Do you remember the feeling of being a new nurse?

OJNA is looking to expand its team of mentors for its new grad mentorship program. Mentors work with mentees for about six months and ease their transition into the world of nursing. Please email ojnamentor@gmail.com if you are interested.

Call for Resume Experts

Do you have experience in HR or as a manager? Join our team of resume reviewers and assist us in reviewing resumes for OJNA members. Email ojnamentor@gmail.com if you are interested.

Join the Journal team

The OJNA Journal seeks strong writers and editors to join our team. Email info@jewishnurses.org if you are interested and believe you have what it takes.

If you are unable to formally join the Journal committee but have an article or other original content you wish to submit for publication in our journal, please review author guidelines at https://jewishnurses.org/journal/author-guidelines/ and either submit your piece online or send it to ojnajournal@gmail.com.

Genetics and Cancer

Yocheved Weinreb, RN, OCN
Toby Bressler, PhD, RN, OCN

If asked about genetics and cancer, the average person, including healthcare professionals, will be familiar with the term 'BRCA' and know its relationship to breast cancer. Some may even know there is BRCA1 and BRCA2; but cancer genetics is about more than just BRCA. Genetics is becoming increasingly essential and its expanding role continues to evolve in the field of oncology.

Our growing knowledge of the human genome has had a significant impact on our understanding of cancer and its treatment and prevention. The breast cancer susceptibility gene, or BRCA, is just one example of the genes identified over the last 10-15 years. Indeed, researchers have identified more than 50 hereditary cancer syndromes. As the methods of genetic analysis continue to improve, it will continue to lead to further discoveries. [1]

Understanding Genetic's Role in Cancer

Within each of our cells is a command center where our genes direct all functioning. Genes make proteins, and each protein in turn has a specific job or message. Some of our genes, called tumor suppressive genes, protect us from cancer by limiting cell growth. They monitor cell division, repair mismatched DNA, and determine cell death. Cancer starts when a gene mutates, or does not have the correct instructions for making its protein. These 'new' instructions—changes in the DNA sequence—disrupt the normal cycle of the cell by either creating an abnormal protein or preventing formation of a protein. [1,2]

There are two types of mutations. Acquired mutations account for the majority of mutations and occur from damage or trauma to cells during a person's life, such as from UV exposure or smoking cigarettes. Germline mutations are inherited from parents and are present at birth. Germline mutations are the cause of hereditary cancers, which account for 5-20% of all cancers. [2]

BRCA and Cancer Risk

Breast cancer is among the most common cancers in women. In 2016, a total of 1,658,716 new cancer cases were reported in the United States. 825,408 cases (49.76%) occured in females and 245,299 (29.7%) of those were breast cancer. [4]

In the late 1980s and early 1990s, the research of Dr. Mary Claire King led to the identification of BRCA1 and, shortly thereafter, BRCA2. Both are tumor suppressive genes that repair DNA strands during the cell replication process (see box for a link to a wild story about Mary-Claire King and the beginning of the discovery of the BRCA gene). Mutations in either or both of the BRCA genes are linked to an increased risk of breast and other types of cancer. The average lifetime risk of developing breast cancer is approximately 12%, and less than two percent for ovarian cancer. In those with a BRCA mutation, the risk for breast cancer goes up to 69-72% and 17-44% for ovarian cancer. [4-6].

Mutations on BRCA1 and BRCA2 each carry a slightly different risk. Mutations on BRCA1 are associated with breast, ovarian, pancreatic, cervical, uterine, and colon cancers. They are also associated with the more aggressive triple-negative breast cancer. BRCA2 mutations are associated with breast, ovarian, pancreatic, gallbladder, bile duct, and melanoma cancers. BRCA1 mutations are associated with a slightly higher risk than BRCA2 mutations alone. [7]

Each mutation carries a 50% chance of passing it to the next generation, and males are not exempt. Male children can also inherit the BRCA mutation and, as carriers, they have the same chance of passing it on to the next generation. Not as much research is available about BRCA mutations in the male population, but a link has been found to increased risk for breast cancer, pancreatic cancer, melanoma, and an aggressive form of prostate cancer for those that carry it. [1,2]

BRCA in the Jewish Population

Despite the relative rarity of the BRCA mutation in the general population, in certain ethnic groups, such as Ashkenazi Jews, mutations in the BRCA1 and BRCA2 cancer susceptibility genes are more prevalent. The CDC (2019) reports that approximately 1 in 40 individuals of Ashkenazi Jewish ancestry has a mutation in the BRCA1 or BRCA2 genes, compared with one out of every 500 members of the general population. [3]

When to Recommend Genetic Counseling

There is variability in the penetrance of breast and ovarian cancer in families that carry the same mutation, and the likelihood that breast or ovarian cancer will develop in a mutation carrier is influenced by many factors. Mutations can occur anywhere along the gene, and the type and location of the mutation and family history are important variables to consider when assessing risk for patients [6]. Those with BRCA mutations and a positive family history of cancer are at a significantly higher risk for breast and other cancers and should be encouraged to consider genetic counseling [4]. A genetic counselor can help them understand the risk to themselves and their family [2]. They may also help guide them through the appropriate screening and prevention tools specific to their risk, and the treatment options if diagnosed [2].

Pharmacogenomics

When speaking of genetics and cancer, it is impossible not to mention the advances in treatment options that have developed. It is important to note that five-year survival rates remain low for many types of cancers [4]. One of every four deaths in the United States is related to cancer, and it remains the second leading cause of death after heart disease [4]. In reality, these are just facts and figures that do not describe the quality of life for those battling and surviving cancer. Long term side-effects from currently available treatments can mean prolonged suffering for cancer survivors [2]. It is clear that fur-

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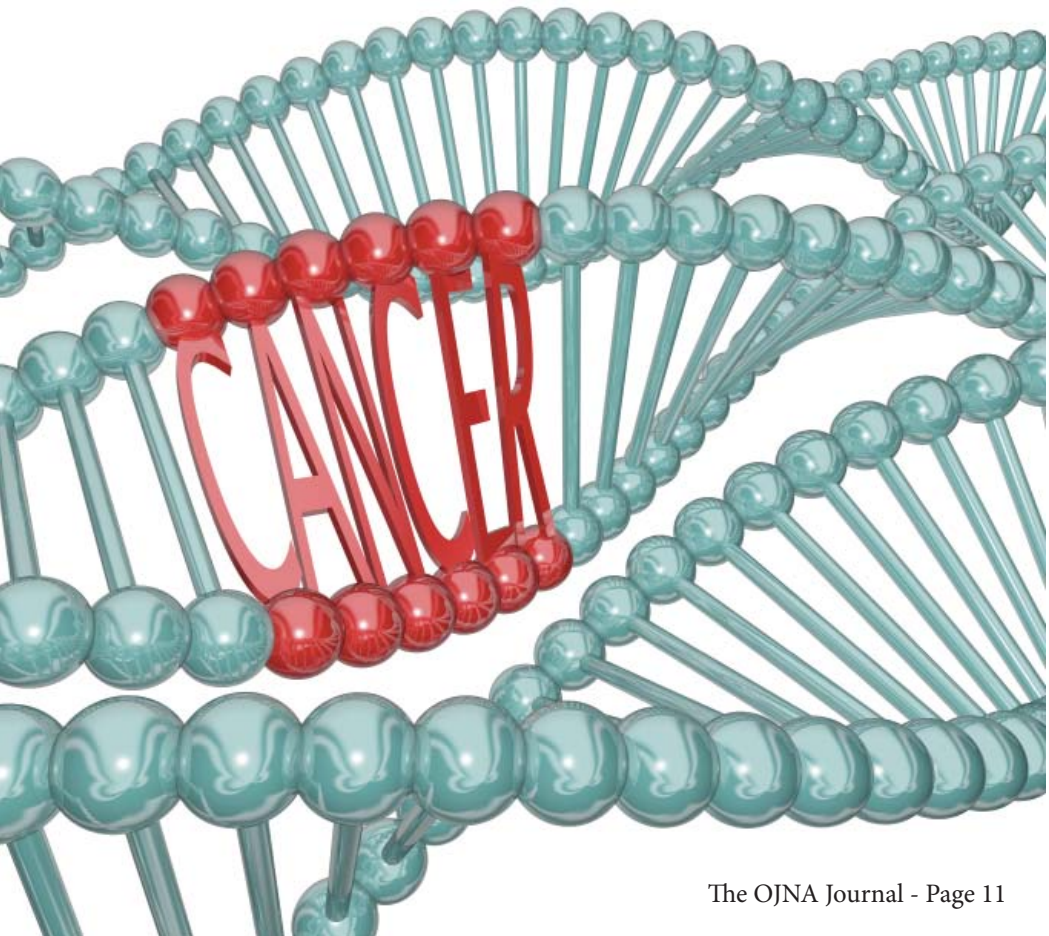

ther research and development of new treatment options is needed. Our enhanced understanding of the genetics behind cancer has laid the groundwork for advancement in early screening, prevention, and treatment options.

Still .the current standard for treatment of most cancers, chemotherapy and radiation are indiscriminate in killing cancer cells and healthy cells. Depending on the regimen, they lead to side effects of varying degrees of severity and permanence. [1]

Tumor DNA sequencing is a genetic test for cancer cells. The identification of specific cancer gene mutations, such as HER2 in breast cancer and EGFR in lung cancer, has led to advances in precision medicine and targeted therapies. Fluorescence In Situ Hybridization (FISH) is one form of cytogenetic testing. Tissue from biopsies may be sent for FISH analysis to inform treatment decisions. [1]

Therapies like immunotherapy/biotherapy are being designed to take advantage of the aberrant unique genetics of specific cancers. Immunotherapies harness the body's immune system to attack the cancer cells. Some monoclonal antibodies act on the cancer cells to make them discoverable and flag them for destruction. Others act as checkpoint inhibitors that work by removing stop signs for the immune system. Another form of immunotherapy involves direct manipulation of a patient's cells. Chimeric Antigen Receptor (CAR) T-cell therapy involves collection of the patient's T-cells to be modified and grown in a lab before being reintroduced into the patient to fight their cancer. This is direct manipulation of the genes. Only a few years ago, that would have sounded like science-fiction and it is now a reality. The market is exploding with these new targeted therapies that are formulated to affect only cancer cells. It almost seems there are new -mabs (monoclonal antibodies) or -ibs (inhibitors) coming out every week, targeting identified tumor DNA specificities. Many more are currently being studied. [1]

One of the greatest advantages of these targeted therapies is the minimized ordeal for patients. The cancer cells are targeted and most healthy cells are not affected, so undesirable side-effects like pancytopenia, chemotherapy induced nausea and vomiting, hair loss, and neuropathies, hallmarks of chemotherapy treatment, are no longer a certainty with treatment for their disease. Although exciting, the treatments are still relatively new. Availability of long-term data on most of these drugs is limited to none and they do carry their own risks and side effects. [1]

There is still a long way to go and much more to discover, but the advances that have already been made in understanding genetics has had a significant impact on the approach to preventing, diagnosing, and treating cancer.

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Dr. Mary-Claire King is a medical geneticist and researcher known for her discovery of the BRCA1 and BRCA2 genes. Scan the code to hear a part of her incredible story.

The Ethics and Dilemmas of Genetic Risk Awareness

Malka Kruger, MSN, RN-BC

Sir Francis Bacon, Thomas Jefferson, and John F. Kennedy are famous thinkers and philosophers who have stated that "Knowledge is power." The human genome contains a vast amount of knowledge; it is the codebook to the human body. The genome contains everything about us, such as eye and hair color, height, facial structure, blood type, and personality. It is also a source for the development of cardiovascular disease, Alzheimer's disease, cancer, and a lengthy list of congenital conditions and diseases, such as autism spectrum disorder, schizophrenia, Duchenne's Muscular Dystrophy, albinism, Tay-Sachs disease, and more.

There are several types of genetic testing available. Among them are preconception testing, where future parents aim to prevent transmission of disease to their child; prenatal testing that allows expectant parents to test the fetus for diseases; and medical DNA genetic testing, where individuals can be tested for diseases that they may be at risk of developing.

With regard to preconception testing, there are tests for genetic diseases that are due to recessive mutations, requiring two carrier parents for the disease to be transmitted to the child, as well as tests for autosomal dominant diseases, where only one parent must have the affected gene for the disease to be transmitted to the child. Dor Yeshorim is an organization founded over 30 years ago after its founder, Rabbi Joseph Eckstein, had lost four children to Tay-Sachs disease. Dor Yeshorim tests for up to 16 recessive conditions and provides results in the form of compatibility reports for potential couples. (doryeshorim.org) More recently, J-Screen has been established to provide more extensive testing for over 200 genetic conditions, including both autosomal recessive and X-linked diseases, and they provide complete carrier status results to every participant by a genetic counselor. (jscreen.org) Preimplantation genetic testing is another form of preconception testing.

Chorionic villus sampling and amniocentesis are examples of prenatal tests that can be used to detect genetic abnormalities. Non-invasive blood work during a pregnancy can also be sampled to detect free-floating fetal cells that are circulating within the mother's bloodstream. [1]

Medical testing may be ordered by physicians or geneticists to identify and manage genetic risks. Alternatively, there are many organizations, such as AncestryDNA and 23andMe, that engage in direct-to-consumer genotyping, and provide reports detailing health risks and predispositions, personal traits, and ancestral information.

Ethical questions abound regarding what to do with the extensive genetic knowledge available today. What power does genetic risk awareness give a person? Many decisions can be made in a person's lifetime based on that knowledge, including choice of a marriage partner, whether and how to have children, the frequency and intensity of health screenings, and health maintenance behaviors such as diet and exercise.

Genetic tests are limited to the information they provide in the clinical situation [2]. Is the information provided by the test sufficiently complete to impact patient care or treatment decisions, or is the information only enough to cause distress and concern without meaningful impact? Additionally, given the ever-evolving world of science, test results that seem irrelevant or unimportant today may be linked to disease risk in the future or vice versa. [3]

Genetic testing brings about ethical concerns of patient confidentiality, biological identity, and implications for family members [2]. In today's world with universal emphasis on patient privacy, and where every healthcare practitioner in the United States is constantly warned about potential violations of HIPAA, genetic testing presents an ethical challenge to practitioners. A genetic diagnosis may translate to a similar risk or finding in one's biological relatives. Does the health care practitioner have an obligation to share information with those relatives if the patient does not intend to do so? Since genetic information is often relevant to one's relatives, is the knowledge of that genetic information only the private domain of *(continued on following page)*

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the patient, or does it already belong to the family, and therefore not require patient consent to be disclosed to family members? In a study performed in the United Kingdom, one participant felt that, "Sharing was important to protect lives, but breaching could violate the patient's 'free will"; however, sharing the information was important to allow relatives to make "timely choices...as soon as their risk was apparent...They saw risk as a 'ticking time bomb" [4].

Even in prenatal genetic testing, the question of future harm raises concerns. Ethical concerns were noted during an Australian study of maternal attitudes toward non-invasive prenatal testing. Termination of pregnancy due to severe disabilities or abnormalities was only one issue discussed in this study. One respondent felt the testing should not be done for conditions that only present later in life. Prenatal testing doesn't consider the medical advances that would take place between prenatal testing and the age of onset. Another respondent felt that prenatal awareness of a child's risk could change the way the child was parented, leading to a "self-fulfilling prophecy" of disease development. A significant fear about prenatal testing was the potential for selecting "designer babies," and the worst case scenario of "encouraging terminations of people (babies) who would have otherwise potentially lived fulfilling lives." [1]

Managing the process of genetic testing is also fraught with ethical considerations. Direct-to-consumer genetic testing allows people to obtain highly detailed information that may be categorized as predictive of susceptibility to disease, diagnostic of a particular condition, or suggestive of care selection [3]. That information is highly complex, and the likelihood of being fully and appropriately understood by a layperson is suspect. This leaves individuals at the mercy of the world of uncurated, often inaccurate, subjective, and non-scientific information regarding how to handle these findings. "In fact, complicated and potentially unreliable data outside the medical and counseling contexts may lead to inappropriate health decisions, which in turn may result in increased health care costs without clear benefits" [3]. It is fairly common knowledge that Angelina Jolie had a prophylactic double mastectomy, as she wrote about it in The New York Times [7]. However, not every person who uses a direct-to-consumer testing service will utilize or have access to the appropriate counseling to determine whether that is an appropriate procedure for them. Other similar examples may be less extreme, but still have significant impact.

The advancement of genetics has designed a category of people who are "genetically at-risk" [5]. Conflict over quality of life, reducing risk, lifestyle changes, elective surgeries, and "uncertainty about whether, when, and the extent to which an illness might actually develop" are difficult issues faced by this group of people. Utilizing proper genetic counseling in combination with any form of genetic testing is essential to allow patients "to make informed decisions, formulate realistic expectations, and use the information obtained through genetic testing to prepare for future health conditions and adapt their lifestyle accordingly" [6].

My second son, 12 years old, has a medical diagnosis of Neurofibromatosis Type I (NF I). While his neurologist has recommended genetic testing, we have not yet done so. My son presents with café au lait spots, axillary freckling, and mild bowing of the long bones, but has yet to develop any of the serious or debilitating aspects of NF I such as fibromas, acoustic neuromas, or Lisch nodules. Monitoring him for development of further signs of the condition is occasionally frustrating and requires several annual appointments with long wait times and scheduling hassles. However, without the definitive answer of genetic testing, monitoring is crucial. Genetic testing would allow for tremendous relief if it ruled out the diagnosis of NF I, yet genetic testing could also determine that his future will be debilitating, possibly painful, and even disfiguring. As long as we don't get the testing done, it might be nothing or may be benign like Legius syndrome, a different condition that looks like neurofibromatosis without further sequelae.

It's an ethical dilemma, but for now, I would rather not know.

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Preconception and Prenatal Tests for Genetic Disorders

Preimplantation Genetic Testing (PGT): Formerly called Preconception Genetic Diagnosis (PGD), PGT is a test that analyzes the DNA of oocytes (polar bodies) or embryos (cleavage stage or blastocyst) for the presence of genetic anomalies. As per its name, this test is done prior to conception. [1]

PGT-A: Assesses for aneuploidies, or the presence of extra or missing chromosomes

PGT-M: Assesses for the presence of monogenic (or single gene) abnormalities

PGT-SR: Assesses for the presence of chromosomal structural rearrangements

Chorionic Villus Sampling (CVS): A prenatal test in which cells of the chorionic villi (tiny projections of placental tissue that have the same genetic make-up as the developing embryo) are aspirated and assessed for genetic and chromosomal abnormalities. The tissue can be obtained through the cervix or through the abdominal wall. It is typically done in the first trimester of pregnancy. [2]

Amniocentesis: A prenatal test in which amniotic fluid is aspirated from the uterus and floating fetal cells are then tested for the presence of genetic disorders, chromosomal abnormalities, and neural tube defects. It is commonly done in the second trimester. [3]

Cell-free fetal DNA (cffDNA): A nondiagnostic prenatal screen in which samples of maternal blood are drawn and free circulating fetal cells within the maternal circulation are assessed for the presence of some genetic and chromosomal abnormalities. Positive tests require additional invasive prenatal testing before irreversible actions are taken.

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HALACHA

Preimplantation Genetic Diagnosis (PGD) in Halacha

By Rabbi Aaron E. Glatt, MD

Halachic issues related to fertility are among the most complicated, controversial, and clinically important subjects that modern day *poskim* face. From the great debates half a century ago regarding rudimentary artificial insemination *shailos* (questions), the science of reproduction has advanced technologically so much so that cutting edge *shailos* nowadays involve every aspect of parentage, genetics, and both chromosomal and mitochondrial DNA issues. And we are at the dawn of an entire new stage of questions as Hashem permits us to develop new advances—true artificial wombs, CRISPR (a powerful tool for editing genomes), and halachic issues revolving around stem/pluripotential cell lines. We will no longer be asking "*who* are the parents", but instead, "*are* there parents"! However, for this article, I will focus on a new but already medically and halachically established technology, preimplantation genetic diagnosis (PGD).

Preimplantation genetic diagnosis (PGD) is a relatively new reproductive technology used as part of an in vitro fertilization (IVF) process to increase the potential for a successful pregnancy and delivery of a healthy non-genetically impaired child. It has brought tremendous happiness to many distraught couples with previously insurmountable medical dilemmas, yet it raises many interesting and provocative questions.

Until PGD, parents carrying various genetic abnormalities would automatically pass these abnormal genes onto their offspring. The clinical manifestations would be dependent upon whether a gene was dominant, recessive, or a mosaic, and upon many other factors. While donor sperm or donor eggs were available, it was impossible to address the underlying genetic abnormality. Thus, until PGD, for couples who wanted children but had abnormal genes, there were limited options, including: a) using donor eggs or sperm; b) prenatal testing with possible termination of a pregnancy (allowable in selected situations according to some halachic decisors); c) no prenatal testing and possibly bringing a genetically abnormal child to term delivery; d) adoption.

However, with the development of PGD, we can now perform genetic testing on cells removed from in-vitro fertilized embryos, to help select the "best" (i.e. non mutated or impaired) embryo(s) to achieve a healthy pregnancy, and avoid the genetic disease or medical issue for which the couple was at risk. The process works as follows: Via in-vitro fertilization, eggs and sperm form embryos in the laboratory, and the embryos mature from a single cell to a blastocyst embryo with differentiation of the ectoderm, mesoderm, and endoderm, after growth for five to seven days. PGD is then performed on appropriately developing embryos by removing just a few cells from the trophectoderm, the outer layer of the blastocyst embryo.

While this removed trophectoderm is being tested for genetic abnormalities, the embryos remain stored in cryopreservation, awaiting test results. When testing is complete and confirmation of embryo viability (i.e. without genetic abnormality) is determined, healthy embryo(s) can be implanted in the mother with the hope that she will become pregnant and carry her child to birth.

Data from many years of PGD in animals and several hundred thousand live births in humans since PGD's inception in 1990, indicate that PGD does not lead to an increase in birth defects. Follow-up evaluation of PGD-born children does not show any evidence for a detrimental effect of the process on growth or neurological development over the first several years of life. Indeed, in embryos where chromosomal PGD testing is performed, one expects *fewer* pregnancies ending in miscarriages due to chromosomal disorders since most abnormalities are identified prior to transfer of the embryos to the uterus. Removal of a few of the trophectoderm cells of the early embryo does not alter the ability of that embryo to develop into a complete, normal pregnancy.

What halachic issues are present with PGD?

Firstly, what is the halachic status of a fertilized egg in a test tube? *Poskim* have ruled that if the electricity/power to refrigerated embryos is shut down on Shabbos, one is not permitted to transgress a Torah prohibition to save those soon-to-be unfrozen embryos. Ergo, they are not considered alive and there is no *pikuach nefashos* (life threatening) consideration to be *mechalel* (desecrate) Shabbos to save them. Therefore, since an embryo is not considered "life", unused embryos may be destroyed without any *retzichah* (murder) concerns, a position at odds with some other religions.

What are the halachic indications for PGD?

Any characteristic that is genetic and has been identified can be selected for via using PGD. Thus, if you wanted blue eyes instead of brown eyes, tall stature instead of short stature, girl versus boy or vice versa, these are all traits or characteristics that PGD could select for. However, just because we *can* make "designer babies" does not mean that we *should*, ethically or halachically.

Indeed, under normal conditions, *poskim* forbid using artificial technologies such as PGD that force one to bypass the normal reproductive process without a good halachic reason. Leaving aside discussions about cost and potential risk taking efforts involved in doing PGD, it would be forbidden (without a good halachic reason) because one is not permitted to utilize contraception to have a "designer" PGD child. Preventing normal husband-wife conception is never something that should be undertaken without serious discussion with a competent halachic authority. However, there are many situations where it is halachically acceptable to perform PGD even though it requires contraception, and even if conception could occur naturally.

HaRav Elyashiv zt"l was asked whether PGD should be allowed to select embryos to prevent serious or life-threatening genetic disorders. His definitive response, that it is permissible, has led to hundreds if not thousands of healthy babies being born under halachic auspices. At such hospitals in Israel, a committee reviews every PGD request to ascertain that it is medically, as well as halachically, appropriate. They take into consideration many medical and social factors, including prior children and gender, severity of the condition being addressed by PGD, and mental states of the parents. Even in hospitals not bound by *halacha*, PGD is often restricted to what are felt to be "appropriate" situations.

One of the most common reasons for PGD is gender selection. In the December 2014 issue of the Israel Journal of Health Policy Research, it was reported that three-quarters of their 308 PGD requests were related to gender selection, and they came from couples where there were already ≥4 children born of one gender. Incidentally, of these applicants, 100% of the Arab and 63% of the Jewish couples were specifically asking to have a son produced by PGD.

In such a situation, both HaRav Mordechai Eliyahu zt"l and HaRav Ovadia Yosef zt"l permitted PGD to be used for gender selection in cases where there were, respectively, five or six children of one gender already born (and none of the other gender). While these poskim *allowed* PGD in these situations, it must be reiterated that there is no halachic *obligation* to do so, even to fulfill the *mitzvah* of "*piryah ve'rivya*" (procreation, and more specifically, having a boy and a girl, according to some poskim). The famous Gemara in Shabbos (127a) states that we will all be asked six questions when we reach 120 years of age. One will be "did we engage in *piryah ve'rivya*"? HaRav Moshe Feinstein zt"l explained that does not mean did we have children, but did we try.

Incidentally, the Maharsha says the question is asking, did we help make *shidduchim* (marriages)? Maybe we can even suggest expanding on that Mahrasha and take the question to its natural conclusion. Maybe Hashem is asking us, did we do everything we could to assist couples unable to naturally have healthy children, to be able to now have healthy children using technology. May it be G-d's will that all people answer that question with a resounding "yes".

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Nurse Practitioner and Physician's Assistant: What's the Difference?

Chaya Milikowsky, MS, AG/ACNP, RN

It is a common occurrence for nurse practitioners (NPs) to be confused with a Physician's Assistant (PA) at some point in their career. Similarly, many nurses and advanced practice registered nurses (APRNs) are asked to describe the difference between NP and PA practice. The confusion and conflation of roles is quite understandable, as NPs and PAs often fill the same jobs and complete the same tasks. Why would a hospital choose to hire one advanced practice provider (APP) over the other, and why should a prospective student choose one path in place of the other?

Practically, both NPs and PAs manage, diagnose, and treat patients. Both providers admit patients and obtain detailed histories, order and interpret diagnostic tests and imaging, and prescribe medications and interventions. NPs and PAs are similarly educated at the graduate level and must pass licensure and certification exams. The median salaries for both professions are fairly comparable, with NPs averaging $107,000 and PAs bringing in $108,600 [1]. Both careers are expected to grow much faster than average[1,2], and are comparable to one another in terms of quality of care [3]. And yet, the NP and PA roles stem from two distinct professions, with differences—some subtle and some more pronounced—that can be detected in their underlying approach to practice, education, license and certification focus, areas of practice, and prescriptive authority.

The most frequently discussed difference between NPs and PAs is their approach to patient care. PAs are educated in the medical model, which is characterized as disease focused. In this model, pathology, physiology, and anatomy become the focus of patient diagnosis and management. In contrast, NPs are educated in the nursing model, which tends to be more holistic and patient focused. NPs are nurses before becoming NPs and must maintain their nursing license throughout their NP careers. During their initial nursing career, as well as through subsequent NP education, patient management focuses on the wellbeing of the patient entirety, which includes mental and emotional wellbeing. In practice, the difference between PAs and NPs may be difficult or even impossible to discern, especially in the inpatient or acute setting. However, the different underlying approach to patient care may account for the NP focus on health promotion and disease prevention and dominance of NPs found in primary care.

Another significant difference between NPs and PAs is the way they specialize and in their areas of certification. PAs are trained in general medical practice, covering all ages, settings, and levels of care. PAs may choose to specialize in specific areas of medicine such as orthopedics, emergency medicine, or surgery. Because their license is that of a generalist, it is fairly simple for PAs to switch from one practice arena to another [4]. NPs, on the other hand, train and attain certification geared towards specific patient populations such as pediatrics, geriatrics, women's health, or neonates. NP certification is further subdivided by acute or primary care. Similar to PAs, NPs can also choose to gain additional specialization in disease or specific medical areas, however, NPs remain limited by their licenses and certifications to specific patient populations [5].

In regards to practice settings, both PAs and NPs work in the outpatient and inpatient settings. However, there is a significant difference in terms of practice setting distribution. PAs tend to gravitate towards inpatient and specialty areas, with only 28% working in family medicine. In contrast, approximately 73% of NPs function in primary care roles [4]. The primary care role is uniquely aligned with the nursing focus on disease prevention, and this explains the heavy presence of NPs in outpatient settings. While NPs can work in operating rooms in the role of First Assist, few NPs choose to work in the surgical arena where PAs abound [4]. Additionally, because NPs function independently of physician oversight in many states, NPs are more likely to work autonomously in practices or clinics run by NPs.

This brings us to consider the difference of practice autonomy between PAs and NPs. Currently, PAs are required to work in collaboration with a physician in most states. The supervision may be indirect, as there is no requirement for direct oversight, but most PAs must have a documented delegation agreement with a physician. Occasionally, a physician must actually cosign orders entered by a PA. [4] NPs, on the other hand, have differing levels of autonomy depending on the state in which they practice. In 22 states, NPs have full prescriptive and practice authority to the full extent of their license without collaboration with any other provider [6]. In 28 states, NPs have either reduced or restricted practice in which one or more element of practice may be limited, or they may be required to have some form of collaboration or supervision from another healthcare provider [6]. The APRN Consensus Model works to regulate national consistency in regards to APRN education, regulation, and practice. Autonomous NP authority is one of the significant elements set forth in this model [5]. The Institute of Medicine also recommends that NPs be allowed to practice independently to the full extent of their licenses [7].

Another commonly noted difference between the two roles is the number of clinical hours required by NP and PA educational programs. PA programs typically require about 2,000 hours of clinical rotations, whereas NP programs only require approximately 500-1,000 hours [8]. When mentioning this vast gap in clinical preparation, it is important to recall that PA programs are generalist programs, while NP programs are focused on specific patient populations and practice areas. While a PA may spend 2,000 hours training in clinical practice, these hours will be spread among pediatric, geriatric,

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and psychiatric patients, and in primary care, acute care, surgical settings, and spanning the gamut of medical specialties. In contrast, the 750 hours of NP clinical rotations will all be in the area of his/her specialization and patient focus. Thus, an NP who ends up working with critically ill adults will have spent an average of 750 hours working with those patients, whereas a PA who ends up working with critically ill adults may have spent considerably fewer clinical hours with that specific patient population. Another factor to consider is that the majority of NP students have worked as nurses prior to entering their NP program; many will have spent years working in the arena in which they hope to specialize. Despite the fewer required clinical hours in an NP program, it is hopefully building on hundreds of patient care hours during one's active nursing career.

Ultimately, both NPs and PAs fill essential roles in today's healthcare arena. With a growing shortage of physicians, especially in primary care settings, a drive to lower healthcare costs, an aging baby boomer generation, and an increased number of people with healthcare coverage due to the Affordable Care Act, the need for advanced practice providers is clear. It is also clear that the care provided by an APP is as effective and safe as that of primary care physicians [3]. It is important to understand our differences, while simultaneously celebrating our similarities and work together to improve quality of care, access to care, and the lives of our patients.

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Member Milestones

RACHEL WEIN, BSN, RN, graduated with her Bachelor of Science in Nursing from Stony Brook University in 2014. She participated in a six-month critical care fellowship at North Shore University Hospital in 2015. After completing the fellowship, she started working for PM Pediatrics, a pediatric urgent care in Forest Hills, New York. She started out as a staff nurse, was promoted to lead nurse, and was recently promoted to office manager in **October 2019**.

ALEEZA DESSAU, MSN, RN, graduated from Columbia School of Nursing with her Master of Science in Nursing in August 2019. She recently passed her NCLEX in **October 2019** and is looking for a job as a pediatric or postpartum bed-

L'VIA WEISINGER, BSN, RNC-MNN, RN-BC, IBCLC, earned her AAS from Phillips Beth Israel School of Nursing in 1996, her Ambulatory Care Nursing Certification in 2008, Maternal Newborn Nursing Core Certification in 2009, her International Board Certified Lactation Consultant certification in 2010, and her Bachelor of Science in Nursing from Western Governors University in 2013. She recently started working as a lactation consultant in The Valley Hospital in Ridgewood, New Jersey, in **August 2019.** She works per diem on the mother/baby unit and as a lactation consultant at Holy Name Medical Center in Teaneck, New Jersey, after having worked there full-time for 11 years. She has worked as a school nurse at various schools across Bergen County, New Jersey, since 2001. She currently works as a school nurse at Naaleh High School for Girls in Ridgewood.

SARAH BRACHA COHEN, MS, RN, graduated from University of Maryland School of Nursing in December 2017. She recently volunteered for a week in Peru with the New York State Nurses Association in May 2019. She worked in the post anesthesia care unit (PACU) at NYU Langone Medical Center until June 2019, when she began working as a fertility nurse at Reproductive Medicine Associates (RMA) of New York. After previously working as an intern in 2010-2011 for In Shifra's Arms, a nonprofit that helps Jewish women with unplanned pregnancies, she officially joined their board in **September 2019**.

MALKA HAYMAN, MSN, AGACNP-BC, graduated with her Master of Science in Nursing in Adult Gerontology Acute Care Nurse Practitioner (AGACNP) from Grand Canyon University in 2018. She recently passed her ANCC certificate for acute care nurse practitioner certification in **October 2019**. She has worked in the operating room at Glendale Memorial Hospital since 2015 and at UCLA since 2016.

ANNA (PEARL CHANA) RIVKIN, MSN, RN, earned her Master of Science in Nursing in Advanced Clinical Management and Leadership from Columbia University in **May 2019**. She has been working in the NICU at Morgan Stanley Children's Hospital in Manhattan since 2013.

SCOTT TOPIOL, BSN, RN, PHN, CEN, EMT, recently became certified as a Mobile Intensive Care Nurse, allowing him to provide advanced life support (ALS) in the field and also provide online medical direction to the paramedics when calling into the hospital. It is one of the rarest specialty certifications in the state of California.

He currently works as a senior nursing instructor for the Los Angeles County Fire Department. Additionally, he works per diem in the emergency room at Cedars-Sinai Medical Center in Los Angeles.

RIVKA POMERANTZ, RN, BSN, IBCLC, received her Bachelor of Science in Nursing from John Hopkins School of Nursing in 2007. She recently started working as a telephone triage nurse in **April 2019** after making Aliyah with her family. Over the years she has worked at St. Luke's Hospital in Bethlehem, Pennsylvania, Abington Memorial Hospital in Abington, Pennsylvania, Medstar Montgomery Medical Center in Olney, Maryland, and Holy Cross Hospital in Silver Spring, Maryland.

TO HAVE YOUR MILESTONE FEATURED IN OUR NEXT JOURNAL EMAIL OJNAJOURNAL@GMAIL.COM

The "Kohen" Gene and the Four Founding Mothers

By Tobi Ash, MBA, BSN, RN

A normal human cell contains 46 chromosomes with 23 chromosomes inherited from each parent. Gender is determined by the X and Y chromosomes. Males have an X inherited from their mother and a Y inherited from their father. Females have two X chromosomes, with one inherited from each parent. [1]

Since males receive the Y chromosome from their fathers, they share this chromosome with a common male ancestor. The mutation rate on the Y chromosome is fairly constant and is usually passed down with any recombination. This means that genetic information on a male person alive today in 2020 is almost the same as his ancient male ancestor. [1]

Most streams of Judaism recognize that Jewish identity is determined by matrilineal descent. Orthodox Judaism recognizes that this ruling occured at the revelation of receiving the Torah but was first codified in the Mishna around 2,000 years ago. [2]

However, the status of being a Kohen is passed through patrilineal descent only. Kohanim are required to be male and directly related to the biblical Aaron. [3]

A study whether self-identifying Kohanim can claim genetic links to Aaron HaKohen was performed by Dr. Karl Skorecki in 1997. This study compared and analyzed two markers on the Y chromosome(YAP and DYS19) of Kohanim and non-Kohen male Jews. Dr. Skorecki determined that the majority of Kohanim, both Sephardi and Ashkenazi, were descended from a single male individual from the Middle East about 3,000 years ago. This marker was much lower in Jews who did not identify as Kohanim. In 1998, Skoreki and other researchers tested six markers as well as additional single nucleotide polymorphisms (SNP) markers. There was a definite difference between the general population and those who identified themselves as Kohanim. [4,5]

An additional study nearly 10 years later examined more markers to separate Ashkenazi, Sephardi, and Mizrachi Kohanim. More than 46% of Kohanim can trace their paternal lineage back to a single male from over 3,000 years ago ("Aaron"). There is a significant low frequency in the non-Jewish populations with this marker, giving weight to the "Kohen gene" hypothesis. [6]

Nuclear DNA, DNA found in the nucleus of the cell, is inherited from both parents. However, there exists another type of DNA, mitochondrial DNA, which are the DNA markers found in the mitochondria. This DNA is inherited from mother to baby. Children of either gender, born to the same mother, will have the same mitochondrial DNA. The mtDNA test can show the origin of an individual's maternal ancestors as well as other relatives derived from their originating maternal line. [7]

A 2006 study in Israel stated that four Jewish women who lived in Europe over 1,000 years ago are the "founding mothers" of 40% of all Ashkenazi Jews. There was evidence of shared maternal ancestry in both Ashkenazi and non-Ashkenazi Jews. If an individual has these specific mitochondrial markers, there is greater than 90% and up to 99% certainty that they are a descendant of one of these women. [8,9]

In 2017, in Israel, Rabbi Yosef Carmel, who is both co-head of the Eretz Hemdah Institute for Advanced Jewish Studies and a senior rabbinical judge on the private Eretz Hemdah rabbinical court in south Jerusalem, requested a woman from the former Soviet Union to have a mitochondrial DNA test to prove her Judaism. Although he stated that "there is no such thing as a Jewish gene," such a test could help determine ancestry for those individuals who lack documentation or family to vouch for a person's Jewish status. However, Sephardi and Mizrachi Jews, as well as about 60% of Ashkenazi Jews, do not carry these mitochondrial markers. [10]

These genetic results highlight that current day Kohanim descend from a common ancestor. In addition, they show fidelity to Torah observance with low rates of intermarriage, despite the upheaval of exile and dispersion into disparate communities worldwide.

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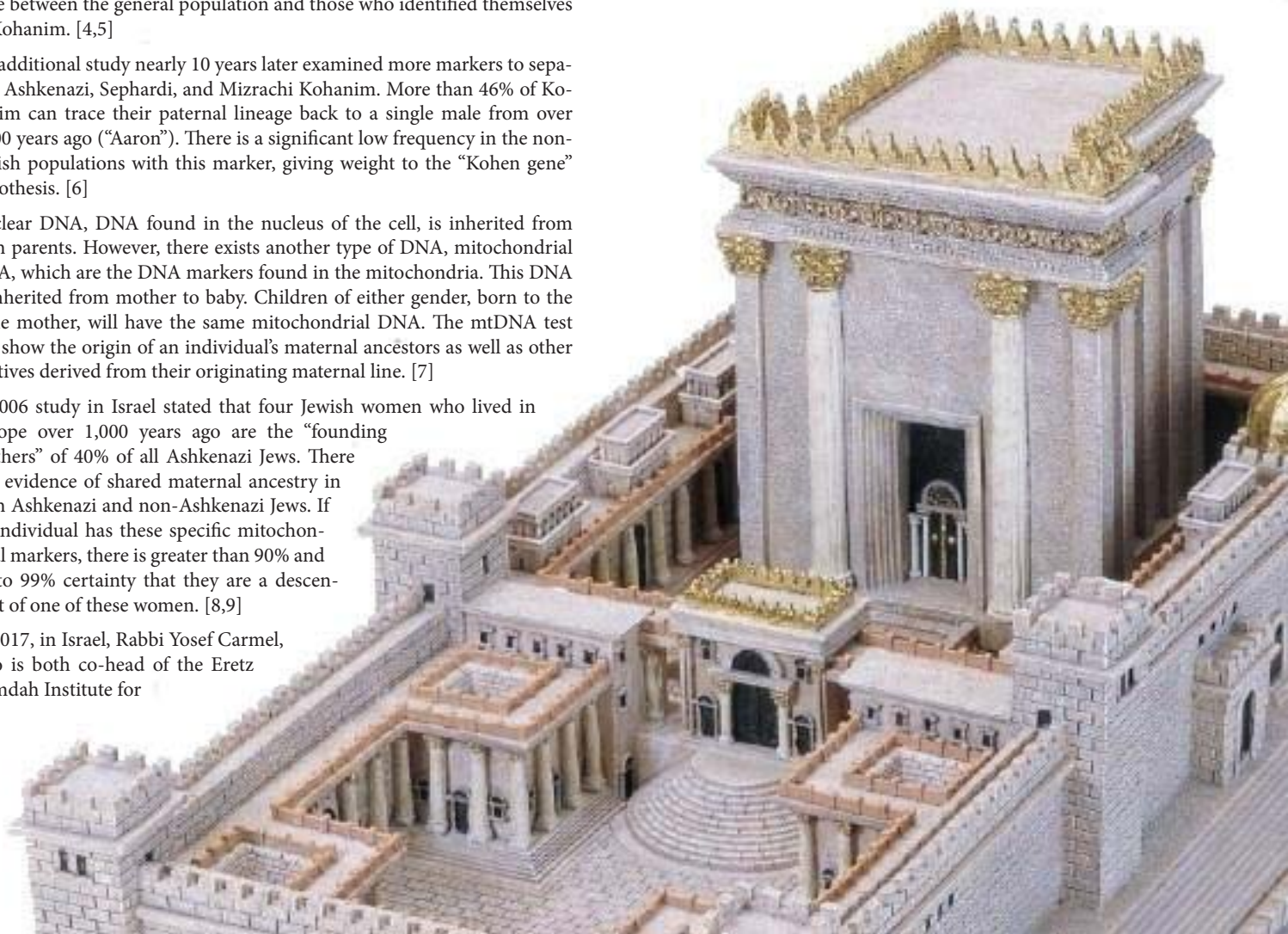

OJNA EVENTS:

In the past few months, OJNA chapters across the United States have held local events where nurses got to network, socialize, and learn.

Pittsburgh held a sukkah social event, complete with ice cream sundaes. Attendees heard from a former cancer patient who shared the way nurses helped her through her cancer journey and how they affected her recovery and ability to bear children.

Los Angeles recently held their first ever OJNA nursing event. They had a great turnout, and so many more nurses have since expressed interest in taking part in future gatherings. In addition to great food and company, Chana Rochel Schusterman spoke about work-life balance and how to deal with the many ethical issues that nurses often have to deal with.

Elizabeth, New Jersey, also recently held their first OJNA event! They enjoyed soup, salads, and desserts, and got to hear from Martha de Crisce on how to navigate the Doctor of Nursing Practice (DNP) project.

The second annual **Chicago** chapter OJNA event was held at the home of Raina Leon. Over 20 nurses from various fields of nursing enjoyed a night of good food, networking and learning. Rabbi Wolf shared a great resource he created to guide non Jewish nurses through the complexities of caring for an orthodox Jewish patient. He was followed by Rabbi Yehudah Meyers who shared some of the most frequently asked halachic questions from nurses along with the Psak from top halachic authorities.If you live in the region and want to be sure to know about future Chicago OJNA events, please email Raina.leon1@gmail.com.

As this journal goes to print, a chapter event in **Miami** is being held in Rustiko cafe. In addition to delicious food and great company, the Miami nurses will learn about integrative and functional medicine by one of their own APRNs.

Please contact info@jewishnurses.org if you are interested in hosting an event in your area.

Stay tuned for additional chapter events that may be happening in your area! We are constantly planning events to help support our nurses and to create a sense of community among our members and fellow Jewish nurses.

ANNUAL CONFERENCE OF THE ORTHODOX JEWISH NURSES ASSOCIATION

ORTHODOX JEWISH NURSES ASSOCIATION

Thursday, June 11, 2020

8:00 am - 4:30 pm

Lander College for Women
227 W 60th St., New York City

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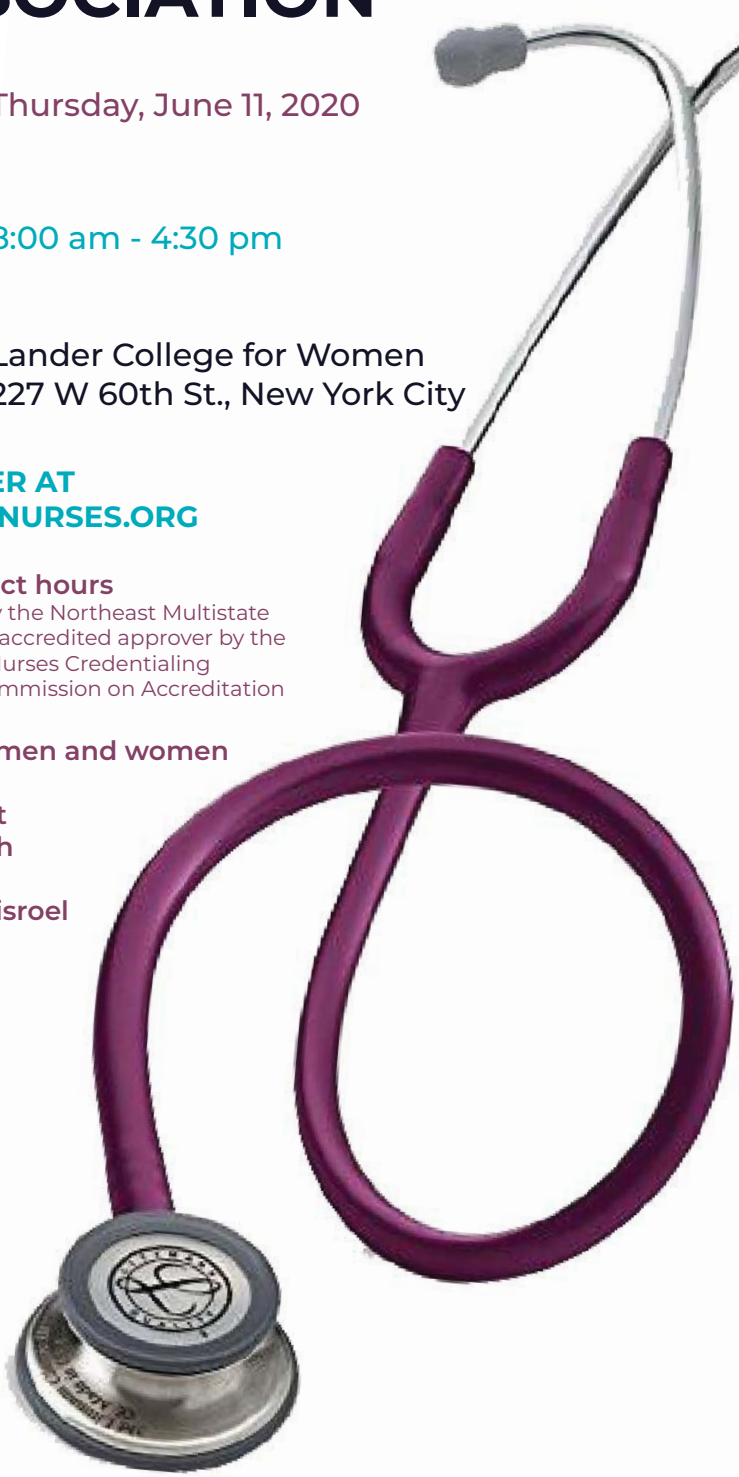
6.5 contact hours
Provided by the Northeast Multistate Division an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation

Open to men and women

Breakfast and lunch

Cholov Yisroel



ACHES AND BREAKS: ISSUES IN CAMP AND SCHOOL NURSING
Chanie Fingerer, BSN RN
L'via Weisinger, BSN RN-C IBCLC

BREATHTAKING: THE BASICS OF MECHANICAL VENTILATION
Hannah Herman, RRT

CROHNS AND COLITIS: LIFELONG CHALLENGES
David Hudesman, MD
Goldie Burstein, RN-C

DYING WITH DIGNITY: HALACHIC PERSPECTIVE ON THE CARE OF A DYING PATIENT
Rabbi Aaron Glatt, MD

HIPAA AND SOCIAL MEDIA: WHAT NURSES SHOULD KNOW
Michael Newman, Esq.

HPV VACCINE: HESITANCY AND KNOWLEDGE GAP IN THE ORTHODOX JEWISH POPULATION
Yardena Mandel, DNP APN FNP-C

LIFE WITH RHYTHM: DRUM THERAPY FOR OUR PATIENTS
Brendan Finnegan

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NURSES TO KNOW

Jordanna 'Jordy' Lipschitz, BSN, RN

Nursing Role: Fertility/Reproductive Nurse

Where do you currently work? What are your responsibilities in this role?

I currently work as the lead nurse at the Somerset, New Jersey, location of Reproductive Medicine Associates (RMA) of New Jersey. Our practice works within a primary nurse framework working one on one with patients from their first infertility visit until discharge. The length of time spent with our patients varies; it can be three months for some and two years for others. Our practice is the primary contact and support throughout the entire process: the diagnostic phase, treatment cycles, and early pregnancy monitoring.

One of the most crucial aspects of my role is establishing a compassionate relationship with my patients. I need to offer emotional and psychological support to patients, provide comfort, anticipate their anxieties, and answer questions and concerns throughout their journey.

During the diagnostic phase, our team coordinates testing for both the patient and her partner, reviews lab results with the couple, and navigates the patient's next steps. During the treatment phase, we schedule cycles (whether it's timed intercourse, IUI, or IVF), provide patient education for treatment plan and medications, follow up lab results, and advocate for our patients behind the scenes. We monitor our patients for the first eight weeks of their pregnancy after which they are discharged to an OBGYN. While discharge due to pregnancy is one of the highlights of my job, it is also emotionally difficult as many women experience negative pregnancy tests, ectopic pregnancies, biochemical losses, and miscarriages.

Do you work in an office setting? Do you go to the OR, lab?

Personally, I work in an office setting. There are other nurses who primarily work in the OR as well as andrologists and embryologists who work in the IVF lab.

How long have you been working in your field, and was this area of nursing your first choice?

As a new graduate nurse, I worked in medical surgical oncology. After giving birth to my children, I got a glimpse of the field of Reproductive Endocrinology and Infertility (REI) and I was instantly hooked. While I've been at RMA for four and a half years, I still love and value the privilege of working in this field and doing what I do each and every day.

Do you require any special credentialing to work in your specific area?

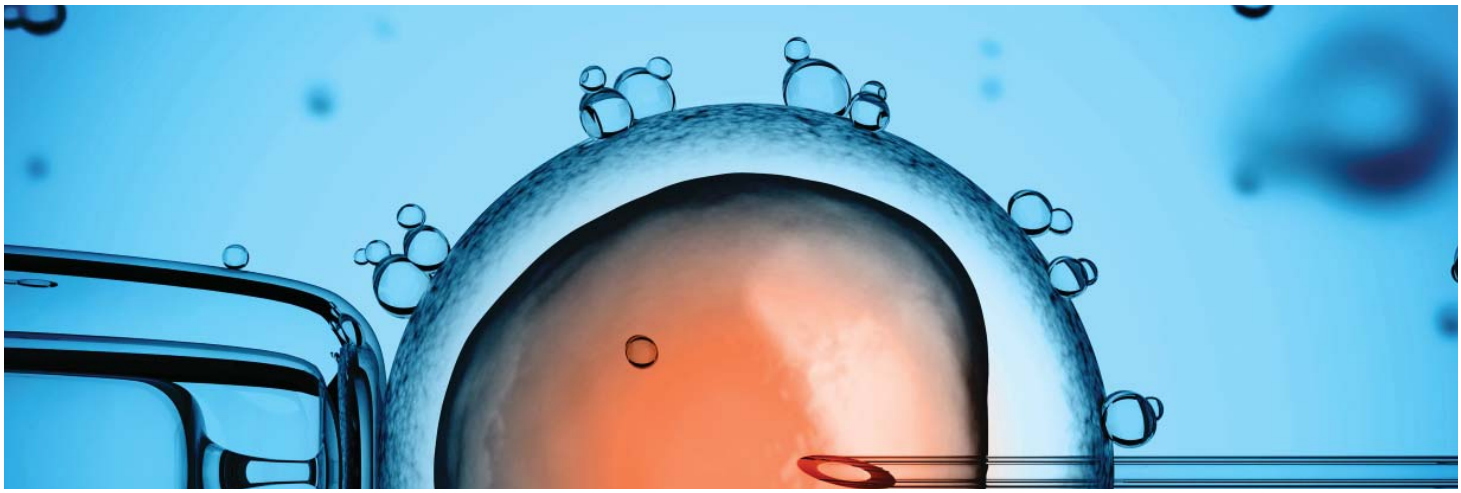
No special credentials are required to start in the field, but I do have an REI nursing certificate and training from the American Society for Reproductive Medicine (ASRM). This training is usually recommended to obtain after working in the field for one year.

What advice would you give to a new nurse in the field?

To a new nurse in REI, I'd advise them to always be willing to learn and to adapt in a constantly-changing field. To flourish, an REI nurse must be able to handle high stress and emotions, be personable, multitask, and have a great deal of patience and empathy. For anyone interested in the field, apply! Some fertility clinics want to hire a nurse with experience, but there are clinics that are willing to train the right person.

How did you hear about Orthodox Jewish Nurses Association (OJNA), and how long have you been involved?

I heard about OJNA from Facebook about two years ago. It's a great resource to connect Orthodox Jewish nurses, share ideas, and support and learn from one another.



If you would like to be profiled in future issues of The OJNA Journal, send a short paragraph detailing your background and role to OJNAjournal@gmail.com.

CAREERS TO CONSIDER

Fertility/Reproductive Nurse

Tziporah Newman, BSN, RN

Job title	Fertility/Reproductive Nurse
Job Description/ Basic Responsibilities [1-3]	▸ Counsel and educate patients and their families on fertility and treatment options, medication administration, pre- and post-op instructions ▸ Act as a liaison between patients, physicians, and other specialists ▸ Research and utilize the latest reproductive technologies, treatments, and advancements ▸ Assist with egg and sperm donor procurement ▸ May conduct scans, draw blood work, perform physical examinations, and assist with embryo transfers ▸ Administer IVF treatments and assist with embryo transfer
Educational Requirements [1,2,4]	RN license ADN at minimum, BSN preferred Certification: Certified Reproductive Endocrinology and Infertility (REI) Nurse through the American Society of Reproductive Medicine
Recommended experience [5-7]	Experience in OB/GYN, reproductive endocrinology, or Women's Health preferred
Salary [8]	Average $78,795/year; $63,000-$85,000
Work environment [1,3]	OBGYN offices, fertility clinics, hospitals, egg donor centers
Typical Work Schedule [5,7]	Typically 10-hour shifts with rotating weekends and holidays, on-call evenings
Job Outlook [3,9]	There is no specific job outlook for fertility nurses. However, there is a projected 12% increase in registered nurses over the next 10 years. Additionally, as technology and research evolves and there are more treatment options for women, the job outlook is likely to in
Suggested Skills	▸ Compassion ▸ Sympathy ▸ Sensitivity ▸ Emotional Support ▸ Good Communication skills

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OJNA RECOMMENDS: BOOK REVIEW

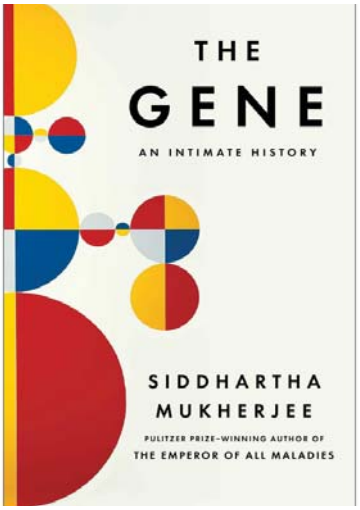
The Gene: An Intimate History

Book Author: Siddhartha Mukherjee

Reviewer: Chaya Milikowsky, MS, AG/ACNP, RN

"Fascinating," "gripping," and "hard to put down" are not the adjectives typically ascribed to a 500+ page nonfiction book. But from the first sentence of the first page, Mukherjee ropes readers into a compelling tale that travels through 2,000 years of history, across vast scopes of scientific endeavor, and then penetrates deep into the elemental questions of our humanity—what makes us human and what makes us unique. Utilizing the thread of his own family's genetic misfortune, Mukherjee is able to personalize the science of genetics and show readers the very real and relatable toll genes exert on our lives and family histories.

The book begins with the discovery of heredity and genes by describing the work and lives of famous figures like Mendel, Darwin, Bateson, and Galton, with a brief excursion to discuss the theories of heredity espoused by earlier Greek scholars. We learn how the concept that genes are discrete, heritable particles of information led to the rise of eugenics, and how that manifested in the social horrors carried out in Europe as well as in the United States. As the field of genetics grew, new questions about the essence and composition of the gene led to the famous discoveries of DNA by Watson, Crick, Franklin, and Wilkens. The next steps in the journey of genetics were those of gene sequencing and cloning. However, the excitement of these discoveries was tempered by the ethical dilemmas regarding the biological and social hazards of actively manipulating lifeforms.



Readers learn how the first genetically engineered pharmaceuticals, such as insulin, were created, as well as the race and drama that surrounded their development. The advent of prenatal testing was an incredible gift for those with family histories of genetic disorders, but also led to the dramatic increase in abortions and neo-eugenics, "the right to be born with the right kind of genes". Mukherjee devotes a few chapters to the impressive task set forth as the international Human Genome Project, to identify and map all of the genes that comprise a human, as well as some of the tensions and truces between the involved players. The final chapters of the book discuss modern themes and current issues being explored, such as the role of genes in race, intelligence, gender identity, and personality.

Throughout the book, the elegant, perhaps almost delicate, prose is buttressed by clear and concise explanations of scientific concepts. Mukherjee is able to explain incredibly complex subjects in ways that even those without much scientific or medical background can appreciate.

Each chapter is prefaced by a variety of witty and nuanced quotes from literature, scientists, and historians that strike at the heart of the text to come. The text itself is peppered with puns, popular references, and fascinating facts that will keep the reader engaged and entertained throughout the long text.

Dr. Mukherjee is an oncologist and the pulitzer prize winning author of The Emperor of All Maladies, which is his epic "biography" of cancer and has since been made into a documentary on PBS. This second book of his is equally impressive in scope and style.

Focus on Gaucher Disease

Gaucher disease is a lysosomal storage disorder caused by deficient activity of the lysosomal enzyme acid beta-glucosidase, which results in the accumulation of its substrate glucosylceramide (GL-1). Progressive accumulation of GL-1 in lysosomes of the macrophage system, particularly in the spleen, liver, and bone marrow, typically leads to progressive spleen and liver enlargement, thrombocytopenia, bone marrow infiltration, and ultimately impaired spleen and bone function. Diagnosis is made by confirmation of bloodwork with a deficiency in acid beta-glucosidase activity in peripheral blood leukocytes, and by the presence of two mutations in the GBA gene.

There are three types of Gaucher disease. Type 1 is most prevalent and occurs in 94% of patients and does not involve damage to the central nervous system (CNS). Gaucher disease type 1 affects up to one in 850 individuals in the Ashkenazi Jewish population. Type 1 generally occurs after infancy, however some patients do not develop symptoms until the onset of adulthood. Types 2 and 3 involve the CNS, and these two types are more rare and potentially fatal, affecting fewer than one in 100,000 individuals.

Symptoms of Gaucher disease include splenomegaly, hepatomegaly, anemia, thrombocytopenia, fatigue, and bone disease. These patients are also at increased risk for hematological malignancies such as multiple myeloma. Clinical progression of the disease ranges from some individuals being asymptomatic to others experiencing life threatening disease progression.

Patients with Gaucher disease report an impaired quality of life. Skeletal involvement, such as thoracic vertebral compression and osteoporosis, may lead to decreased ability to perform normal activities of daily living. They may experience severe bone pain and impaired mobility.

Cerezyme is an enzyme replacement therapy that was approved for use in 1994 for children and adults with Gaucher disease type 1. Cerezyme has been shown to improve anemia, thrombocytopenia, reduced spleen and liver enlargement, and decreased cachexia.

Sanofi Genzyme sponsors the ICGG Gaucher Registry, which is the preeminent resource on Gaucher patient data. This registry was created more than 20 years ago, and its mission is to increase the understanding of Gaucher disease and improve outcomes for patients with this disorder.

For more information, educational resources, and support, contact Sanofi Genzyme at 800.745.4447, option 3. More information is available at Genzymesupportservices.com and registrynxt.com.

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OJNA RECOMMENDS: BOOK REVIEW

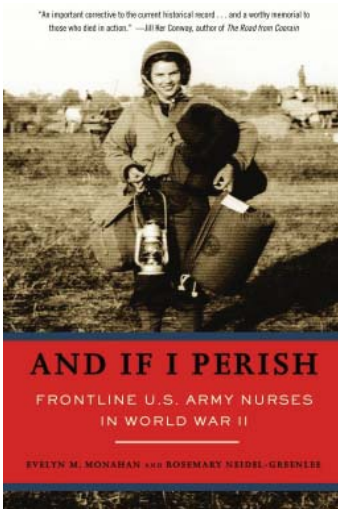
And If I Perish: Frontline U.S. Army Nurses in WWII

Book Author: Evalyn Monohan and Rosemary Neidel-Greenlee
Reviewer: Elka Hertz, RN, BSN, CEN

'I will go and if I perish, I perish.'

Those words, familiar to many of us from the Book of Esther, have been said or lived by 59,000 women who voluntarily risked their lives for their country. These women were U.S. Army nurses during World War II. These nurses were sent to North Africa, deployed on the Normandy beaches, or worked on the Italian front. They were nurses like you and me; coming from comfortable lifestyles, working in hospitals where patient and staff safety were of highest concern, with hardly any idea of what to expect in a war zone. Some of them brought along stylish clothing, thinking they would have time for their high heeled shoes. The nurses had to learn and adapt very quickly and did not always have time to prepare. Not all who landed on D-Day beaches made it to shore, and those who did make it found themselves literally in hell on earth. Living mostly on C-rations, without showers or change of clothing and with minimal sleep, they still fought on and worked tirelessly to care for those in need.

Throughout this book, I read anecdotes about nurses having to duck under operating tables during surgery as bullets and shrapnel came flying through the tents. I read about heroes who would not leave their patients. I also read about the tight camaraderie and friendships that were formed, the teamwork that came through when needed, and the devastation of losing peers and patients alike. Although hospitals, including field hospitals covered by large swaths of white cloth with big red crosses painted on them, were off limits for enemy fire, the Germans did not abide by the rules of war, and the field hospitals were often strafed with bullets from low flying planes. While reading this book, I could feel the mud and cold in which they slept, the hunger they faced, and I could imagine the unhygienic conditions in which they lived in those traumatic war years.



What I did not find in this book were any complaints from the nurses. They were heroes, though unsung. For decades, these women were mostly ignored, even by the military and Veterans Affairs (VA). These women typically did not come forward to share or speak about their experiences as frontline nurses and prisoners of war. And they were not asked until Evelyn Monahan, a retired psychologist, and Rosemary Neidel-Greenlee, a nurse herself, decided to make sure that these women and what they endured will not be forgotten. This book gives eyewitness, firsthand accounts with plenty of details, but never has the feeling of a history textbook. I got pulled into the drama and devastation of personal lives while learning about the frontlines of WWll. Like Queen Esther, these nurses were committed; they knew they were needed, put their fears aside, and said; "I must go, it is my duty."

References

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JOB OPENINGS:

Are you looking for an RN/NP job? Do you know others looking for one?
Paying members of OJNA can view job details or share information about jobs on our job board. Non-paying members who have job information to share should email info@jewishnurses.org.

Recent Job Postings:

1. **Nurse needed for teenage girls sleepaway camp in Greenfield Park, New York**
2. **Nurses needed for sleepaway camp for children with medical needs. Located in Glen Spey, New York**
3. **Nurse practitioner for homebound patients. Willing to train new graduate. Located in Brooklyn/Queens, New York**
4. **Case managers needed for a 12 week project. Work remotely from home**
5. **Nurses needed for rehab facility. Full time and part time shifts available. Located in Brooklyn, New York**
6. **Nurses needed for ketamine infusion clinic. Per diem position located in North Jersey**
7. **School nurses needed for various schools in New Jersey**
8. **Nurse needed for girls' sleepaway camp, Camp Shoshanim in the Poconos, Pennsylvania**
9. **School nurse needed in Manhattan Day School in New York City**
10. **Director of Nursing position available in Lakewood, New Jersey**
11. **Nurses needed for special needs school, Gan Ezra, in Rockland County, New York**
12. **Nurse needed in rehab facility in Livingston, New Jersey**
13. **Nurse needed for boys sleepaway NCSY camp**

Mentorship Program Write-Up

Mara McCrossin, MSN, NP

Being a new graduate nurse can be challenging and scary. The questions begin to multiply. Will I find a job? Where will I work? What department will I work in? Will I have to work the night shift? Is this going to be the right fit for me? Will my religion be a factor in all of this? How will I navigate Shabbos/Yom Tov? What do I need to do to succeed at an interview?

As I think back to the time when I was a new nurse, I had wished that there was someone who could guide me through this experience and help answer these questions. Even after I started working as a new graduate nurse, I had so many questions about practice or scheduling and I wished I had a fellow nurse who understood my unique struggles and could be there when I needed to vent my frustrations or share my successes. At the time, I asked whoever I could find, whether it was a co-worker who may not have understood the ins and outs of being Jewish, or a friend who was not in the nursing field but understood the other aspects of my life. Throughout that time, I always wished that there was someone who truly understood what nursing was about, who knew what it was like to be a Jewish nurse. Back then, I wished that there was someone to guide me and who perhaps may have had experiences similar to mine.

Years later, when I joined OJNA, one of the first things I wanted to do was give back and help guide others who were probably having the same first experiences that I had. This was how the New Graduate Mentorship Committee was born.

Since the program started in March of 2018, we have matched up 32 new graduates with experienced nurses. We have done our best to match up new nurses with experienced nurses in their field of interest. So far, we have nurses in women's health, NICU, neurology, labor and delivery, emergency room, Med-surg, and general pediatrics. The new graduate connects with their mentor via phone or email, can ask any questions that may come to mind, and vent their frustrations about a busy day at work. The expectation for the mentor is that they make themselves available whenever they can and work out times to check in with their new graduate mentee on a regular basis.

This program has blossomed over the short time it has been in existence, and we definitely see the benefit for those that have opted to use it. Due to this success, the OJNA has recently gained IRB approval to study the outcomes of our work with hopes to share our accomplishments with the greater nursing community.

To that end, the OJNA will be conducting its first research study!

The primary purpose of this study is to explore the role of mentoring within the context of Orthodox Jewish nurses who either have been the recipient of mentorship or serve as a mentor. The dual aims of this study will measure mentoring experiences and explore the experiences of mentors and mentees of Orthodox Jewish nurses. The secondary aim is to determine the degree to which Orthodox Jewish nurses perceive the importance of characteristics of the mentor and mentoring relationship, as well as the level of satisfaction with the mentor and mentoring relationship.

Here is a testimony from one of our newest members of the New Graduate Mentorship Program:

"I highly recommend the OJNA New Graduate Mentorship Program. When I graduated from nursing school, I didn't have much direction when it came to applying for jobs. My mentor gave me lots of practical advice on how to land my first nursing job. When I was anxious the night before an interview, she conducted a mock interview for me, and even helped me decide what to wear to the interview. **In the end, I got the job that I wanted,** and I'm so grateful to my mentor for all of her help." - *Rena, RN*

Institutional Review Boards

The role of an Institutional Review Board (IRB) is to ensure protection of the rights and welfare of human subjects involved in a research study. An IRB should consist of a diverse group of members who vary in gender, cultural background, race, and sensitivity to issues such as community attitudes. The IRB must include five members from scientific and non-scientific disciplines and at least one person who is not affiliated with the research institution. Generally, IRBs consist of physicians, PhD level scientists, nurses, and attorneys.

Governed by FDA regulations, the IRB will review research materials and protocols before and during an ongoing research study. An IRB has the authority to approve, deny, and require modifications to proposed research studies, and all IRBs are equally bound by federal regulations of research review and guidelines.

Any institution, facility, or hospital can register with the FDA to create their own IRB, and facilities that frequently perform research involving human subjects will do so. However, this is not required by law. A facility or institution can use an outside IRB to grant approval and monitoring of its research study.

Once IRB approval is received, human subjects involved in the research study will need to sign informed consent that they are voluntarily willing to participate in the study and fully understand what is involved. During this process, participants should be educated, at a minimum, on the details and procedures of the study, length of expected participation, and potential risks and benefits. Depending on the actual study, more information such as compensation and treatment for potential injuries may be required to be shared with the participants.

Fda.gov

Hhs.gov

Newborn Screening

Shevi Rosner, MSN, RN-C

The newborn screening (NBS) program is a universal, international, and highly successful screening program which originated in the United States in the 1960s under the influence of Robert Guthrie. Guthrie wanted to find an explanation for his child's mental retardation, and during this quest, he created a test to detect phenylketonuria (PKU) which is a metabolic disorder characterized by mental retardation, learning difficulties, spasticity, seizures, developmental delay, and congenital heart disease. Detection and testing for PKU led to the justification of screening programs to detect other detrimental, and sometimes fatal, conditions that are not apparent at birth. [1] As PKU was the first disorder for which a screening test was developed, many nurses and clinicians still refer to the NBS as "PKU".

The NBS program is well established and includes initial screening, detection, education, diagnostic follow up, treatment, and management of disease. Early detection, diagnosis, and intervention can prevent death or disability. [2]

The recommended uniform screening panel (RUSP), a list created by the Secretary of the Department of Health and Human Services (HHS), recommends those diseases and disorders that should be part of the universal NBS program. The RUSP is formed based on evidence that supports the potential screening benefit, the ability of individual states to actually screen for the disorder, and the availability of effective treatment options. Diseases can be nominated to be added to the RUSP, and this process involves a rigorous assessment and analysis before an official decision by the Secretary of the Department of HHS has been made. Some well known diseases that were recently added to the RUSP include spinal muscular atrophy (SMA) in 2018, pompe disease in 2013, critical congenital heart disease in 2010, and severe combined immunodeficiency (SCID) in 2009. [3]

Decisions on what to include in the individual NBS panels are based on social, ethical, and political considerations in each state. Ultimately, each state chooses which tests to include in its NBS program. To date, there are more than 40 genetic, endocrine, and metabolic disorders that are tested for in the NBS program.

Many of the disorders included in the NBS are inborn errors of metabolism (IEMs), which are a complex group of disorders that exhibit clinical symptoms due to an error in genetic code. This error leads to an inadequate rate of enzyme activity affecting one's metabolism. Delay in diagnosing and treating IEMs can lead to adverse outcomes, such as neuropsychological dysfunction, mental retardation, and even death [1]. Some of the most commonly tested diseases in the United States are PKU, congenital hypothyroidism, galactosemia, sickle cell disease, hearing loss, cystic fibrosis, and medium-chain acyl-CoA dehydrogenase deficiency. [2,4]

Laws and regulations for the NBS program vary from one state to another, and nurses need to be familiar with the state's laws and regulations in which they practice. In New York State, a single NBS test is generally performed after 24 hours of life and must be done before hospital discharge. For infants in the neonatal intensive care unit (NICU), an initial NBS sample must be obtained before starting a blood transfusion or administering total parental nutrition (TPN). Blood transfusions may mask the presence of hemoglobinopathy or galactosemia, and TPN may alter results of acylcarnitines and amino acids, and therefore secondary samples must be collected in these two specific situations. A second sample is obtained at 48-72 hours of life, and a third sample is taken at either 28 days of life or day of discharge, whichever occurs first. A repeat NBS collection may be requested due to poor sample quality or a positive NBS result. Parental consent is not required for NBS collection in New York as it is required in Maryland and some other states. In contrast to New York's regulations, Idaho requires testing on all infants at 24-48 hours of life, with a second test at 10-14 days of life, and parents are allowed to refuse the NBS collection for religious reasons. States such as Vermont and Minnesota allow parents to opt out for any reason. [4,5]

Millions of babies are tested annually prior to discharge from the hospital. A few drops of blood are obtained via heel stick and placed on special, filtered paper. In some instances, blood samples can also be obtained from an artery or vein. Attention must be placed to ensure there are no blood clots in the specimen, nor underfilling or overfilling of the circles on the filtered collection paper. These situations would render the NBS sample unsuitable for testing.

Once dried on a flat surface for a minimum of three to four hours, the NBS sample is mailed to a special laboratory for testing within 24 hours of collection. The lab can identify more than 40 inherited metabolic disorders in around two to three minutes. Results are given to the providers, and abnormal NBS results are relayed to the parents with an additional specimen sent to the lab for testing.

It is crucial for nurses and advanced practice nurses to be up to date on the nuances of the NBS program, RUSP, and proper collection protocols. The results of the NBS are critical in enhancing and saving the lives of infants diagnosed with these rare, yet critical and life-altering diseases.

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AMERICAN NURSES ASSOCIATION ANNOUNCES THE ORTHODOX JEWISH NURSES ASSOCIATION AS ITS NEWEST ORGANIZATIONAL AFFILIATE

SILVER SPRING, MD – The American Nurses Association (ANA) welcomes the Orthodox Jewish Nurses Association (OJNA) as the latest addition to its list of organizational affiliates. This will bring the total number of ANA's partner organizations to 38. OJNA is an organization that aims to address professional issues related to Orthodox Jewish nurses and to serve the special needs of its members.

"ANA is excited to begin this new partnership because together we strengthen our resolve and commitment to continue the work of advocating for all nurses from every background," said ANA President Ernest Grant, PHD, RN, FAAN. "Organizational affiliates like the Orthodox Jewish Nurses Association are essential to our work in reaching that goal by bringing valuable insight and unique perspectives to the table."

OJNA was established in 2008 when a new nurse saw the need for a forum to discuss issues specific to Orthodox Jewish nurses. OJNA now hosts annual educational conferences as well as various networking, educational, and career advancement events across the country. The OJNA offers a mentorship program for new graduates, resume building, and writing assistance. Its biannual nursing journal is peer reviewed, and membership spans across the U.S., with chapters in Canada and Israel.

"On behalf of the OJNA Board of Directors, we are delighted to begin this partnership with the American Nurses Association. The affiliation of the Orthodox Jewish Nurses Association with ANA will enhance the inclusion and diversity of ANA while we continue to focus on the needs of our members," said OJNA President Elisheva Rosner, MSN, RN-C.

ANA and its organizational affiliates seek to unify all nurses across different health care settings and areas of expertise as a powerful force to transform health care. ANA's organizational affiliates have specialized knowledge and experience with a targeted segment of the nursing community, while benefiting from a strong public presence, influence on government policy and the support of ANA. Read more about ANA's organizational affiliates.

About the American Nurses Association
The American Nurses Association (ANA) is the premier organization representing the interests of the nation's 4 million registered nurses. ANA advances the nursing profession by fostering high standards of nursing practice, promoting a safe and ethical work environment, bolstering the health and wellness of nurses, and advocating on health care issues that affect nurses and the public. ANA is at the forefront of improving the quality of health care for all. For more information, visit www.nursingworld.org.

About the Orthodox Jewish Nurses Association
The Orthodox Jewish Nurses Association (OJNA) is an organization that aims to meet the unique needs of its members while promoting nursing professionalism. OJNA provides a forum for discussion of issues that are specific to Orthodox Jewish nurses, arranges networking and educational events, and seeks to be a voice for Orthodox Jewish nurses around the world. For more information, visit www.jewishnurses.org.

MUSINGS

On Heritage and Heredity

Rabbi Elyakim Milikowsky, MA

Spiritual DNA [sDNA] is a term one often hears bandied about, but it is worth considering, from our Orthodox Jewish perspective, whether this cliche has any real meaning.

The Talmud (Yevamos 79a) famously says that there are three markers of the Jewish People: they are *rachmanim, baishanim v'gomlei chassadim,* they are merciful, humble and perform acts of loving kindness. Only those who have these three traits are worthy of being members of the Jewish People.

Reading this passage seems to be the Eureka moment when we discover our Spiritual DNA and it sounds right. This description of the sDNA of the Jewish People seems to be reflected by the seeming overrepresentation of Jews in nursing and other caring professions. But at the same time, accepting that we do have a real and intrinsic sDNA raises other questions.

Where does this sDNA reside? Can it be found in a physical genome? Could that somehow mean that converts might not have Jewish sDNA? How about someone who is genetically Jewish but wasn't raised as such? Is it perhaps mitochondrial?

I believe the answer to these questions is encoded in Bereishis 18:19, the source the Talmud brings for the inclusion of chesed in the Jewish sDNA. In relation to the question of why God chose Avraham as the progenitor of the Jewish People, the verse says: "יצוה את בניו ואת ביתו ושמרו דרך ה' לעשות צדקה ומשפט למען אשר - For I know him, that he will command his children and his household, and they will keep the way of God to do righteousness and justice". Avraham was chosen because he would command and teach loving kindness to his children and those who chose to join his household.

This point is underscored in a Mishnah in Pirkei Avos (5:22) which expands the core elements of our sDNA. The Mishnah tells us that one who has a generous eye, a lowly spirit, and a humble soul is a student of Avraham Avinu. Conversely, one who has a stingy eye, an overly-elevated spirit, and a haughty soul is a student of the evil Bilaam. Whether we are considered a descendent of Avraham or Bilaam does not depend on who bore us. It is dependant on who we learned from. One's spiritual heritage is not conferred by a strictly physical father, but by one who is also a teacher and a guide. Avraham Avinu is equally the father of the entire Jewish People, those who are his physical descendants and those who choose to join his household.

Our unique and essential sDNA does not lie in our physical genes and cannot be transmitted organically nor automatically. Spiritual DNA is found in our hearts and minds, not our blood and bone. To the extent that we have this sDNA within ourselves it is because our parents and mentors consciously chose to transmit it to us. If we want to impart our sDNA to our children, we must create our our own link in the eternal (double helix?) chain

We can all be teachers, and our students need not be only those within our families and community circles. Nurses who are proudly Jewish display their sDNA through their actions and interactions that embody mercy, humility, and kindness. With these traits, we teach all the inhabitants of our world that a person can be, and is meant to be, more than just an expression of his physical DNA. This is the truest fulfillment of the heritage of Avraham Avinu whose life's goal was to teach the entire world "the way of God to do righteousness and justice".

Rabbi Milikowsky is a rebbe and administrator at the Yeshiva of Greater Washington. While not a nurse himself, he has been married to one for many years and talks about creating an OJSNA for nurse spouses.

MEET THE TEAM:

Chaya Milikowsky, MS, AG/ACNP, AG/ACCNS, RN, received her Master of Science in Clinical Nurse Leadership from the University of Maryland School of Nursing in 2010, after which she went directly into critical care nursing. In 2015 she received a post-masters certificate as an Adult/Gerontology Acute Care Nurse Practitioner and Clinical Nurse Specialist from the University of Maryland School of Nursing. She continues to work in critical care and is a nocturnist in the intensive care unit at MedStar Montgomery Medical Center. In addition to her role on the OJNA Board, she is also on the Advanced Practice Council of the MedStar Hospital system. She lives in Silver Spring, Maryland, with her husband and five children.

Tobi Ash, MBA, BSN, RN, received her Bachelor of Science in Nursing from Barry University in 1998, her Masters in Business Administration from Nova Southeastern University in 2001, and is currently completing her Ph.D. at Walden University. Tobi is the Director of Women's Health Care at Nano Health Associates in Miami Beach. Tobi has more than 20 years of experience working with families, with an emphasis on women's health. She is a member of Sigma Theta Tau International Honor Society of Nursing and served the Nurse position on the Health Care Advisory Committee for the City of Miami Beach for two consecutive terms. She sits on the board of the Greater Miami Jewish Federation, LimmudMiami, EMES Initiative, NCSY Southern Region, Miami Beach Garden Club, Helping Hands, and is the former chair of Ohel South Florida Advisory Board. She lives in Miami, Florida.

Toby Bressler, PhD, RN, OCN, is the Director of Nursing for Oncology and Clinical Quality in the Mount Sinai Health System. She received her BSN Magna Cum Laude from SUNY Downstate, Master's degree from NYU and her PhD from Molloy College of Nursing. Dr. Bressler's research interests focuses on the Orthodox Jewish community, care of the cancer patient, the promotion of palliative care and quality of life of patients and families. She has authored more than 50 articles, chapters, and posters and has presented widely. Dr. Bressler is an elected officer with the American Nurses Association NY, Vice Chair of the Nursing Section of the New York Academy of Medicine, Chair of the Eastern Nurses Research Society Palliative Care Research Interest Group and also served as a Jonas Policy Scholar with the American Academy of Nursing. She lives in New York.

Sarah Bracha Cohen, MS, RN, received her Bachelor of Arts in Health Sciences from Hebrew Theological College in 2013 and her Master of Science in Nursing and Clinical Nurse Leader from the University of Maryland School of Nursing in December 2017. She is a member of Sigma Theta Tau International Honor Society of Nursing, the Honor Society of Phi Kappa Phi, and the American Nurses Association. She is a fertility nurse at Reproductive Medicine Associates (RMA) of New York. In addition to her work for the OJNA Journal, she volunteers for the Vaccine Task Force of the EMES Initiative, is a birth doula and is on the board of In Shifra's Arms, helping Jewish women with unplanned pregnancies. She lives in New York City.

Tziporah Newman, BSN, RN, received her Associate Degree in Nursing from Middlesex County College in 2012. She received her Bachelor of Science in Nursing from Thomas Edison State College in 2014. She currently works as a field nurse with medically fragile children. She recently took on the additional role of nurse supervisor. She previously worked as a director of nursing for a home health care agency, supervising and teaching nurses and home health aides. She is a member of the American Nurses Association, the New Jersey State Nurses Association, and the Society of Pediatric Nurses. She actively volunteers for Chai Lifeline and her local Bikur Cholim. She lives in Highland Park, New Jersey.

Yocheved Weinreb, RN, OCN, received her Bachelor of Science in Nursing from New York University in 2011. She started her nursing career as a bone marrow transplant nurse and found her passion in oncology nursing. She recently transitioned to working in supportive oncology and palliative care at Mount Sinai Downtown. She is a member of the Oncology Nursing Society and was chosen for the Mount Sinai Emerging Leaders program. She is currently pursuing her Masters in Nursing Education from Chamberlain University and hopes to be an oncology nurse educator or nurse administrator in the future. She lives in Brooklyn, New York.

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