HINA PATEL FOUNDATION FOR SICKLE CELL DISEASE

By Bhavana Patel, RPH, President of the Hina Patel Foundation

HISTORY OF HPF

- Girls Scout Gold Award
- Started in 2010
- Hina's Journey with SCD and Bone Marrow Transplant

THE ROLE OF HPF

- Support Research
- Continuing Medical Education
- Community Awareness: Run/Walk – Sept. 16 2017, Health fair, School
- Support Group: Pizza Party, Annual Picnic, aide in transportation for health care need, help to get medications covered
- Get Connected
- Camp Hina
- Camp Crescent Moon
- Holiday Giving: December
- Welcome Baskets : For babies and new members
- India Outreach: Screening, Comprehensive SCD center in Rumla, SCD Health Camps, Surgeries, Sponsor children

Support Research

- Sickle Cell Disease is a debilitating disease and impairs the quality of life. Bone marrow transplant is the only possible cure but carries its own risk. For those with a successful transplant with few complications, the results can be a great improvement in the quality of life, but for those who suffer the severe complications; it can lead to serious problems and may be life-threatening. Thus, the decision to undergo a bone marrow transplant for sickle cell disease is a complex one, involving medical, family, personal, and ethical considerations.
- Gene therapy is a new approach to the treatment of many blood cell diseases that may provide an alternative to transplantation from another person. In gene therapy, the bone marrow is collected from the patient's own body. Next, the stem cells are isolated in the laboratory and a normal copy of the relevant gene (one that produces normal hemoglobin) is either added to the cells or the defective gene of the patient is directly repaired. The gene-corrected stem cells are then transplanted back to the patient after they receive chemotherapy. In theory, gene therapy should be able to have the same benefits as a bone marrow transplant from another person, but not have risks for graft versus host disease, since it is an autologous (stem cells harvested from self) transplant from the patient. Research to develop methods for effective gene therapy has been ongoing for more than 20 years. It has been applied successfully to treat more than 50 infants with severe combined immune deficiency (SCID –also known as "bubble baby disease"), with recovery of their immune system after transplant of their own gene-corrected bone marrow. However, gene therapy can have a unique risk in that the methods used to add or fix the gene in the stem cells can trigger overgrowth of the cell, and in some cases caused a leukemia-like disease in treated patients. Newer methods to add or correct genes have been developed and are being studied in current trials for SCID and other diseases. Similar approaches for gene therapy of sickle cell disease are being developed and clinical trials will begin in the near future to determine if they provide a safe and effective way to treat sickle cell disease.
- The research for stem cell gene therapy for sickle cell disease is a program of UCLA conducted by Dr. Kohn. His multi-disciplinary disease team includes experts in stem cell gene therapy, clinical bone marrow transplantation, and the care of patients with sickle cell disease.
- With your continual contributions and support for research, Hina Patel Foundation remains hopeful that efforts of the UCLA team will find a safe cure for sickle cell disease.

Family Support

- For individuals with Sickle Cell Anemia, leading a normal life requires the involvement and commitment of friends, family, employers, school teachers, principals, doctors and nurses in various cities and hospitals. It truly takes a village to battle this disease. People with sickle cell start to have signs of the disease during the first year of life, usually around five months of age. Symptoms and complications of sickle cell disease are different for each person and can range from mild to severe depending on the genotype. There is no single best treatment for all people with sickle cell – treatment options are different for each person depending on the symptoms. In addition to the physical symptoms, the reoccurring pain causes many patients emotional turbulence. Therefore, it is important make sure emotional and morale support are provided to those affected through support groups. Hina Patel Foundation (HPF) hosts support group meetings via pizza parties, family picnics, and one-on-one conversations over the phone. All of the sessions promote self-sufficiency by discussing various health complications, sharing information about new treatments, and providing nutritional guides. Our organization also visits those that are hospitalized to provide moral support, companionship, and often offer prayers for their rapid recovery.
- Families battling with chronic debilitating diseases often face great financial burdens, including transportation costs and copayments associated with treatment. Sickle cell patients are no exception. The HPF Assistance Program is designed to alleviate some of these transportation costs for families.
  We provide support to patient families in the form of gas cards and writing refund checks upon proof of receipt for parking, copayments and other transportation cost.
- **Education**
- HPF works diligently to provide an understanding of the pathophysiology of Sickle Cell Disease and recent advances in the diagnosis and treatment of acute and chronic complications to healthcare providers as well as to patient and their families. This understanding leads healthcare providers and patients to make better informed decisions as to the most effective level of care and maintenance for the disease. A primary objective is that healthcare providers, especially in Kern County, become more aware of the recommendations for health maintenance and screening for all patients with Sickle Cell Disease. Over the next few years, the aim is to provide optimal performance in clinical and emergency settings.

Camp Hina

- Traveling can sometimes be difficult for those suffering with Sickle Cell Disease, so the foundation has developed a strategy to give patients and their families a break. An all-expenses-paid getaway to the mountains serves up the perfect reprieve! Fun activities like dancing, painting, board games, and cooperative BBQ's offer creative opportunities to stimulate the body and mind. Music around the fireplace and peaceful hikes provide the perfect setting for tranquility and relaxation. A nurse practitioner will accompany the group in case of an emergency. The event promises to be the start of a rich, exciting tradition for Sickle Cell Disease patients.

Holiday Giving

- One of HPF's favorite activities each year is playing Santa for local Sickle Cell Disease patients. Armed with beautifully wrapped gifts and bright smiles, foundation volunteers travel to homes and hospitals in the area to make special deliveries. The pretty stockings, holiday treats, and gift cards never fail to bring joy to the recipients and their families. But the giving is not one-sided – the resilience, courage and hope that each patient demonstrates always inspire gratitude in the hearts of the volunteers as well. HPF board member, Sejal Simson, echoed those sentiments, expressing how the event "gives me great pleasure to see the joy on the faces of each child when they receive their gifts. It embodies the spirit of Christmas!"

Run/Walk

- The annual Hina Patel Foundation 5k/10k Run/Walk started as Hina's brainchild. She wanted to increase awareness in the community about her disease, so she organized the first event in 2008 as her Girl Scout's culminating project. Since that time, the event has increased in scope and effect, developing into one of the most popular 5k/10k races in the city.
- Every September, Sickle Cell Disease month, foundation organizers, student volunteers, eager runners and walkers, patients and their families, and members of the community come together to support the cause. Organizers arrive before sunrise to prepare the park for hundreds of attendees. Poster boards line the perimeter, providing information about Sickle Cell Disease for everyone in attendance. Music fills the air during registration. Families of local patients proudly wear their team t-shirts, adding color and joy to the festivities. Local vendors donate food items and water bottles to runners preparing for the race. To create awareness for community members, Sickle Cell Disease patients give testimonials about their personal experiences. The National Anthem is sung, and the racers are off!
- But that's not the end – the 5k/10k Run/Walk simply serves as an introduction to a full day of festivities. After the race, volunteers serve a variety of healthy snacks and sweet treats to weary runners. Smiles appear like magic on the faces of children interacting with a visiting clown, getting their faces painted, or having their hands adorned with henna. Victorious racers pose for selfies with fellow runners and friends. Booth attendants encourage attendees to sign up to Be The Match or donate blood at the Houchin Blood bank.
- Each year, the event has grown in size and impact. Approximately 150 people have signed up to become bone marrow donors, and hundreds more have donated blood at the event. Hina's dream of creating awareness of the disease in her local community has been realized, and it continues to serve as a fun, engaging method for generating support. Join us for the next 5k/10k Run/Walk this coming September!

Welcome Baskets

- To help create awareness and provide support, the foundation makes baskets. They are for parents who've just discovered their baby has sickle cell anemia or patients who've just been diagnosed with the disease. The baskets include a water bottle, a pill organizer, a heating pad, a thermometer, a blanket, and socks. The baskets also include a booklet explaining the different types of sickle cell disease. It explains what the disease is, how to care for and treat sickle cell patients, and the importance of always taking your medication. The booklet also includes information about Hina Patel Foundation, the sickle cell support groups, and why it's so important to connect with a local community to reduce stress and maintain optimism.
- Creating awareness about sickle cell is my passion, and I know that these baskets will help us achieve that goal. Your financial contribution will make a difference. Each basket costs only $50.00 roughly the same amount as a dinner out. Together, we can let patients in Kern County know that there are support groups, great doctors, and a caring foundation focused on helping patients with sickle cell disease. Thank you in advance for your support!

India Outreach

- Comprehensive Sickle Cell Center
  - **Comprehensive Sickle Cell Center – Rumla , Navsari, Gujarat, India**
  - The inspiration for a comprehensive Sickle Cell Disease center came when Dr. Kannar, Chief District Health Officer-Navsari, mentioned how a young patient had died from a multiple organ failure during pregnancy. Dr. Kannar stated that he was “shaken up” by the young women’s death and “did not want to just sign death certificates, but rather do something to prevent these types of tragedies.” His vision became reality when the facility was constructed under the guidance of Dr. Yazdi Italia and Bhavesh Raicha of Valsad Blood Bank, Government of Gujarat and Hina Patel Foundation. The center opened to the public on June 19th, 2016, world sickle cell day.
  - The center is the first comprehensive sickle cell center in Gujarat. It offers screenings for newborn babies, prenatal screenings, patient counseling, 24-hour emergency services, pain-crisis management, oxygen therapy, Hydroxyurea management, blood transfusions, laboratory work, plus x-ray and ultrasound services. The center is staffed by primary care doctors, nurses, and sickle cell counselors. A hematologist visits the center twice each month to manage patients who are on Hydroxyurea, the only medication approved to reduce sickle cell pain crises. The center has the ability to refer patients to outside sub specialists if necessary.
  - The facility also provides other services and promises to have a huge impact in the region. Dr. Jagdish Patel, the doctor in charge of the center, recently announced that meals will be provided for all admitted patients in Rumla. While it may seem normal to provide meals for admitted patients per practices in the USA, such is not the case in India. The meals provided by the center offer hope and help keep patients strong while going through treatment. With over 1500 registered Sickle Cell Disease patients within 30 miles of the Rumla center, the facility will be well-utilized. Dr. Kannar’s realized dream will save lives and help to reduce the suffering of countless patients and their families.

India Outreach (cont.)

- Medical Camp
  - Valsad District has two thousand sickle cell disease homozygous patients and eighty-thousand sickle cell trait heterozygous patients. Hina Patel Foundation (HPF) in collaboration with Valsad District Health Department and Valsad Raktadan Kendra (VRK) organized two comprehensive health care camps for sickle cell disease patients of Dharampur and Kaprada Taluka on November 22, 2016 and November 24, 2016. Camps were held at Dharampur State Hospital which was equipped with pathology lab, x-ray machine, and ultra-sound serivces which were necessary for diagnosis and treatment planning. A total of hundred and thirty-six patients attended the two camps and all were seen by medical officer or pediatrician, depending on the age group. Some with complications got referred to Hematologist and Orthopedic Surgeon who were present on site. One hundred and nine patients were started on Hydroxyurea, forty-two patients received x-rays, six required ultra-sonography, and all one hundred and thirty-six got CBC lab investigation. Two patients required blood tranfusion which was provided free by VRK. All medical services, investigations, and medicines were provided by the Dharampur State Hospital, except for the Hematologist, Dr. Nirav Buch, who graciously volunteered his time both days. A thorough counseling of sickle cell disease patients regarding the crisis management and how to live with sickle cell disease was carried out by members of HPF along with a kit with necessary medicines, a thermometer, hot water bag, dressing material, and educational material, all of which was supplied by HPF.

India Outreach (cont.)

- Surgeries
  - Avascular Necrosis (AVN) of femoral head is a common complication in sickle cell disease patients, occuring many times with bilateral hip involvement, causing disabling defomities. The necrosis is caused by reduced blood flow to the bone and occurs in 12-15% of sickle cell disease patients. Out of the one hundred and thirty-six patients who attended the camp, thirty-eight were referred to and examined by orthopedic surgeon and twenty-five of them were reported to have AVN. Among those diagnosed with AVN, fifteen patients were identified by the Orthopedic surgeon as candidates for hip replacement surgery. Dharampur State Hospital has agreed to provide Orthopedic surgeon and the operating facility provided the cost of the joint is covered by government grant or with help of donations from charitable organizations such as HPF. Results and reccomendations were discussed and explained in detail to the patients by HPF members and local counselors. Local agencies will follow up with pre-op requirements and HPF will help in soliciting funds for joints, if government grant is not available. One patient was referred to a gastroentrologist for gross enlarged spleen and arrangement made to follow up for surgery if recommended.

India Outreach (cont.)

- Sponsorship of Children
- During our initial visit to India in 2011, we learned how extreme poverty and lack of health care affected children and their families dealing with complications of sickle cell disease. A visit to a family in a rural area of Valsad, Gujarat was a huge eye opener. The family home was a little hut made of bamboo sticks, dry grass, no windows, a floor made of cow manure, no running water or electricity, and no toilet. The father, mother, and three young children lived in a space approximately (how many square feet?). The father was a day laborer in the construction industry, and he made $1.65/day when he was able to find work. Mom provided fulltime care the children. Two of the children were suffering with sickle cell disease and required frequent visits to government run free hospital. The government hospital was overcrowded with patients, severely under-staffed, and often bereft of life-saving medications. Whenever one of the kids got sick, both Mom and Dad would have to go to the hospital with all three children because there was no one to take care of them at home. The hospitals had no accommodations for the parents or children to stay and no food for them to eat. The children had to miss the school and the father had to miss the work, leaving the family completely destitute. The situation was so precarious that the mother refused to send the children to school during the rainy season, fearing that the cold rain would trigger a pain crisis. This would initiate another long family long trip to the government hospital, missed school days for the other children, and more days of work and pay missed for the father. Seeing this persistent cycle of sickness and poverty made us realize how blessed we are in the USA and how much of an impact we could make with just a few dollars each month. Consequently, we decided to adopt ten families whose children had sickle cell disease.
- Valsad Blood Bank, Dr. Komal Desai, and Pooja Desai helped HPF identify ten families whose situations were similar to the family mentioned above. Through the family adoption program, HPF provides the cost of hospitalization at a private hospital, life saving medications, transportation costs to attend school, costs for school books, back packs, school uniforms, crutches, raised toilet seats, and more. Our goal is to provide resources to families in extreme poverty, bring hope and smiles to their faces, and ultimately share the blessings of God with His children.

India Outreach (cont.)

- India Screening Project 2012
- Sickle-Cell Anemia is a major public health concern in India. Its diagnosis and management has remained inadequate, and national control programs do not exist in tribal populations. The basic facilities to manage the patients undergoing crises are usually absent. Also, systematic screening is not a common practice. For most individuals, the diagnosis is usually made when a patient presents with severe complications from Sickle Cell or often times the diagnosis isn't made at all due to the fact that patient will die from the complications before testing can be performed. Simple, cheap, and very cost-effective medicines such as penicillin to prevent infections, folic acid to increase red blood cells, and once-weekly anti-malaria medications (Larium) are not affordable for most Sickle Cell patients in these tribal populations.
- The knowledge, expertise, and financial aid in the management of Sickle Cell Disease which is available in technologically advanced countries must be shared with less developed countries where patients die at alarming rates.
- The cost to screen a village is approximately $4,000 and to provide maintenance medication for an individual with Sickle Cell Disease is roughly $25 per year.
- With your support and donations we can make a difference to work toward eliminating this disease by screening and educating the tribal regions of India.