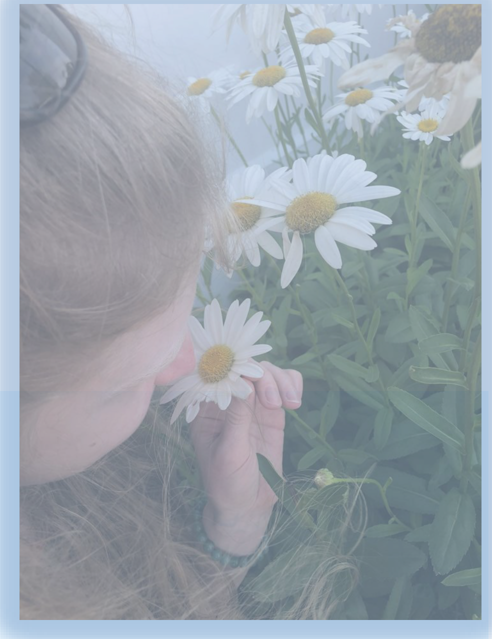
HPS Network Inc.

2018 Annual Report

Hpsnetwork.org

OUR MISSION

TO FIND A CURE FOR HERMANSKY-PUDLAK SYNDROME AND IMPROVE THE LIVES OF INDIVIDUALS AND THEIR FAMILIES WHO ARE LIVING WITH THE DISEASE UNTIL THEN.



Dear Friends,

When working with the Conference Committee this year the theme “Life is Sweet” received positive votes. I am a cup half full person and generally an optimist but I stopped to wonder if it was true. Is Life Sweet?? Lately I wasn’t sure. We have had such loses this year and so many mountains to climb. We are working and working and the time passes seemingly without giving us time to catch the precious breath we struggle to maintain. Feeling like I'm slipping into a pool of pessimism, I repeated the title in my head again. The cloud lifted as I thought “yes it is; when we’re together!” Life is Sweet When We’re Together! It is, it really is because I could not imagine being without all of you. Hope lies in the eyes of the children’s pictures that are posted on our social media. It lies in the calls to the office with questions and thoughts. It lies in the brains of our doctors, the hands of the hearty and the hearts of our frail. Together as the HPS Network we are making it special. Thank you to all of you, members, families, friends and supporters who lift us up both emotionally and financially. In a time when money is tight and spirits are consumed, you all were the most generous than ever, in both. I am so blessed to know you and love you and have you in my life, fueling each day with hope and determination. With these friendships come a profound call to action. I never rested my resolve (or panic) since the day I looked in my daughters eyes. Now I have so many that have inspired me in the relentless pursuit of a cure. We are a little engine with a mighty track. Your support has kept me on the journey, grounded in steel, constantly moving. God Bless all of you for everything you have done for us. Look at what you helped us accomplish!

Love Donna

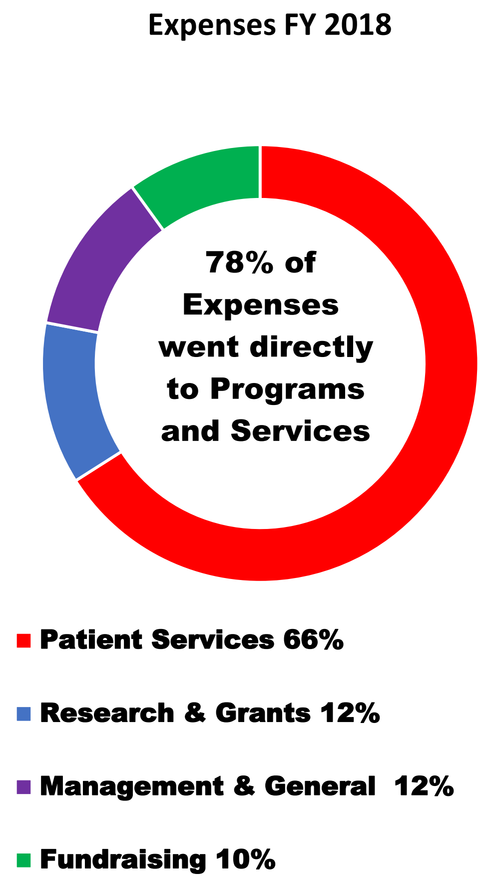
Our Impact

The HPS Network supports individuals and families by providing the hope of education, research and fellowship. It is dedicated to lightening the anxiety and heartbreak for the newly diagnosed and offering the healing proactivity for those struggling with the chronicity and isolation caused by this rare disease. It is relentless in its quest to fund, engage and inspire research working closely with incredible scientists. The programs delivered provide meaningful contributions to the quality of life of our beloved community. It is with your help, kindness and generosity that we have been able to provide:

- Since August of **1992** a contact registry has been maintained & through the years compiled entries from **1368** individuals with HPS
- **25** years of maintaining an uninterrupted website resource
- To respond to calls, **2** registered nurses answer questions and provide healthcare referrals and recourses
- **396** weekly parent conference calls were provided with an average of **5** familes per call in Spanish
- **99** monthly parent conference calls were provided in English
- **23** monthly conference calls were provided for HPS Adults with an average of **8** people on the call
- **2** calls per week are counseled in the TIPS (Transplant Information and Peer Support) program
- On average **1** new family is joining the Network per week
- **22** Volunteers spent **57** hours writing **179** Thank you Cards for two fundraisers (the Oysterfest and the Jingle & Jazz Gala)

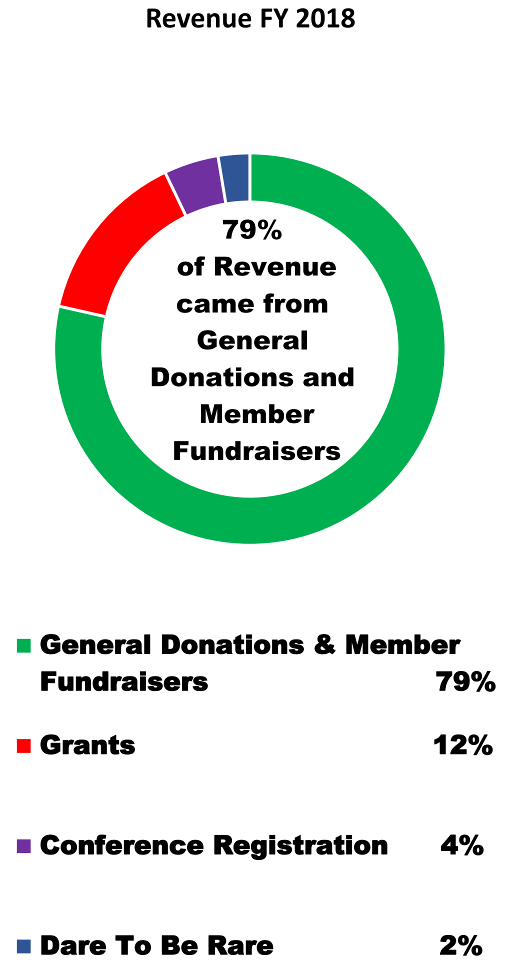
Several recipients have called the office telling us how thoughtful our members were in their kind words. Flavia (our blood drawing, poop collecting volunteer and supporter) mentioned that she teared every time she read the words in her THANK YOU written by Maryann Canter, "Mother Nature does not give up her secrets easily but she can be persuaded through effort and determination. You are a part of the cure!"

Expenses FY 2018



Education & Public Awareness	$	28,307.02
Member Services - Healthcare	$	23,396.65
Member Support Services	$	26,598.22
Conference - New York	$	98,145.12
Puerto Rico-Conference & Outreach	$	23,599.26
Research Initiatives & Grants	$	37,159.65
Management & General Support	$	37,591.85
Fundraising	$	29,325.32
Total Expenses		**$304,123.09**

Revenue FY 2018



General Donations & Member Fundraisers	$	191,053.91
Grants	$	34,935.00
Concert	$	31,968.10
Conference Donations	$	23,300.55
Under 5%		
Annual Campaign	$	12,749.22
Conference Registration	$	10,985.00
Dare To Be Rare	$	6,335.20
Oyster Festival	$	2,669.78
Total Revenue	$	**313,996.76**

Member Services

Serving those affected by Hermansky-Pudlak Syndrome is a huge part of what we do at the HPS Network. From helping families get access to accurate testing, to helping them with their new diagnosis, to guiding families through the many challenges that come with living with HPS, we think of ourselves as one large family helping one another. Here are some of the ways we serve families.

Families affected by Hermansky-Pudlak Syndrome attend 25th Annual Conference

The HPS Network held its 25th Annual Conference March 9 – 11, 2018 at the Long Island Marriott in Uniondale, N.Y.

The HPS Conference allows families affected by the syndrome to meet others as well as hear from the world's leading experts on the syndrome. Sessions included both fun activities as well as serious topics on how to manage living with HPS. Some of the sessions included:

- Pre-conference workshop for mothers of children with HPS.
- HPS 101 – a overview of the basics of HPS for new families, or those that need a refresher.
- GI Wish I Felt Better – a chance for those affected with the bowel disease of HPS to hear about new research and network with peers.
- Managing the bleeding of HPS – a session presented by a hematologist familiar with HPS.
- Women's Health – an overview of the unique medical issues experienced by women with HPS given by an OBGYN experienced in helping women with HPS.
- Social Aspects of Raising a Child with Albinism
- Information about preparing for lung transplantation
- A Top Chef-style cooking contest

Zumba classes

Sunday's program focused on current research about HPS and included speakers such as:

- William Gahl, Clinical Director of the National Human Genome Research Institute
- Kostas Alysandratos, a fellow at Boston University's Center for Regenerative Medicine, who spoke about stem cell research.

- Lisa Young, an HPS researcher at Vanderbilt University, gave an update on the growing number of HPS Centers as well as HPS research.
- Samuel Seward, one of the only physicians with a clinical practice for those with HPS, spoke about the HPS Standard of Care.

"I always enjoy reconnecting and spending time listening to the information doctors and researchers present to us," says Amber Klein, a person with HPS, "It always inspires me to make a difference and better everyone's lives."

"This (the conference) is a true lifeline of information that I will be able to share with my own doctors to help others. Each one of us is a piece of this puzzle of HPS," Jill Pounders, a person with HPS.

Getting Tested:

For many families, the HPS Network plays a key role in their diagnostic journey. Because HPS is rare, physicians are often unaware of the syndrome or how to accurately test for it. The HPS Network helps out by providing families with information about the syndrome, and directions for physicians about how to order the test. We also can help families problem solve through the process if barriers arise. In the last year, we helped 91 people get tested for HPS.

HPS By the Numbers:

91—Number of people the HPS Network helped get tested for HPS in the last year.

HPS By the Numbers:

305—Number of attendees at the 25th Annual HPS Conference.

Getting the Diagnosis:

When someone tests positive for HPS, we are there to give them information and a listening ear that understands what it feels like to get this news. We've all been there. New members are added to our contact registry so they can be sent information and made aware of any research or clinical trials that might be of interest. We also send a new-member packet full of information for them, their families and their physicians about HPS and the standard of care. For the kids, we also include a doll donated from Giving Dolls. This year, we added 61 people with HPS to the patient registry.

Ongoing support

After the diagnosis, the HPS Network offers ongoing support to families affected by the syndrome. This takes the form of in person and online events, groups and services designed to help those with HPS lead the healthiest life possible.

Wallet Cards

Medical Health Alert

Patient has rare genetic disorder:
Hermansky-Pudlak Syndrome
Scan back for emergent information

For further information contact:
HPS Network
www.hpsnetwork.org
info@hpsnetwork.org
(516) 922-4022
1-800-789-9477

The HPS Network offers registered families wallet cards that have a QR code on the back. Should they need to explain HPS in an emergency department or new doctor's office, the physician only needs to scan the code with a free app on their phone, and they will be given medical information about HPS including several key publications.

Support and information calls

The HPS Network offers informational calls to educate as well as support families. The calls are held once a week for Spanish-speaking parents of children with HPS and once a month for English-speaking parents. These calls are sponsored through a partnership with the New York Lighthouse for the Blind. We also offer monthly calls for adults in English and Spanish. We plan to roll out webinars in the coming year.

Facebook communities

No one understands living with HPS like the people who do it every day. The HPS Network hosts several Facebook groups. The groups are moderated to ensure information exchanged is accurate, and that anyone needing assistance can be connected with someone who can help. We host groups for parents of children with HPS, adults with HPS (a multilingual group) and for Spanish speaking families.

As of publication, membership in the groups is:

Adults with HPS—124

Parents of children with HPS—121

Spanish-speaking families—88

The HPS Network Facebook page has 1,462 likes and 1427 followers.

Twitter presence

As of print time, the HPS Network has 900 followers on Twitter. Our Twitter followers tend to be more medical-oriented than member families.

Instagram presence

The HPS Network has 767 followers on Instagram. Most of our followers on this platform are younger members and families or the family of members.

HPS Network e-newsletter

Members of the HPS Network get the e-newsletter for free. It contains news about what is going on within the HPS Network, news about research or other news that may be of special interest to our members. Currently, the e-newsletter has 152 subscribers. Our open rate is 32 percent, compared to the non-profit industry average of 21 percent. The e-newsletter goes out roughly once a month, depending on how much news there is to report. Sometimes we double up two months, and sometimes, if there is a lot going on, we put it out twice in a month.

HPS Network partners with ATS for Patient Education Day in Puerto Rico

The HPS Network partnered with the American Thoracic Society (ATS) to host a patient education day at the Sheraton Puerto Rico Hotel and Casino in April.

The day featured presentations about treating and living with the bleeding, gastrointestinal, ophthalmological and pulmonary complications of HPS as well as options such as palliative care and lung transplantation. Presenters included:

Dr. Bernadette Gochuico, Attending Pulmonologist at the National Human Genome Research Institute, NIH

Dr. Fernando Torres, Head, Lung Transplant and Pulmonary Hypertension Program at the University of Texas Southwestern Medical Center

Dr. Jesse Roman, CEO of the Jane and Leonard Korman Respiratory Institute, Philadelphia, PA

Dr. Wilfredo De Jesus Rojas, Pediatric Pulmonary, San Juan

Dr. Enid Rivera, Director of Pediatric Hematology at the Pediatria, Eocuola de Medicina, UPR

Dr. Natalio Izquierdo Encarnacion, Pediatric Opthamologist at Escuela de Medicina, UPR

Carmen Camacho, MA LSW, Board of Directors and New England Coordinator, HPS Network

Nancy Suarez Lee, Board of Directors, HPS Network and double lung transplant recipient

Hilda Cardona, Board of Directors, HPS Network, PR Regional Coordinator

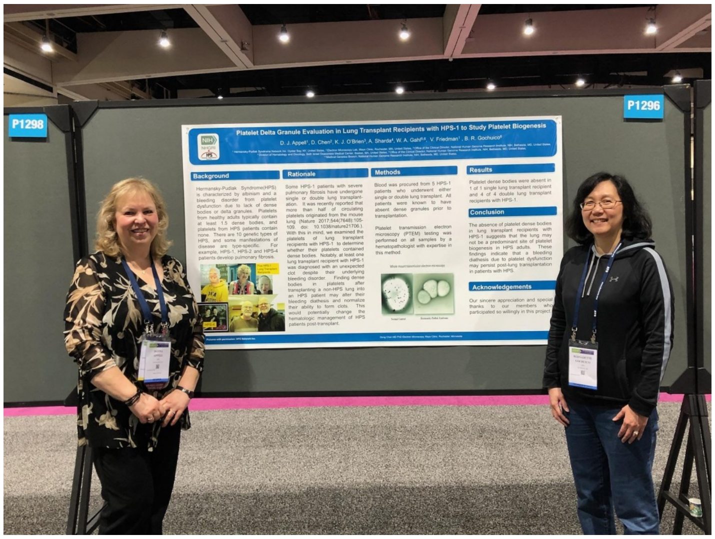
Scientific Activities

The scientific activities of the HPS Network involve supporting research financially as well as through activities that facilitate participation by patients.

HPS Network partners with ATS Foundation to award two-year research grant

The HPS Network is partnering with the American Thoracic Society to fund a two-year research grant for the lab of Dr. Souheil Y. El-Chemaly, MD at Brigham and Women's Hospital in Boston. The research will investigate angiotensin II type 1 receptor trafficking in lung fibroblasts and its role in HPS lung fibrosis. The grant is for $40,000 a year for two years. Half of the funds are provided by the HPS Network and they are matched by funds from the ATS Foundation.

HPS Network presented a scientific poster at the American Thoracic Society International Meeting



The HPS Network presented a scientific poster at the American Thoracic Society (ATS) International Meeting in San Diego based on its own research. The poster was titled Platelet Delta Granule Evaluation in Lung Transplant Recipients with HPS 1 to Study Platelet Biogenesis. It was reported in the April 2017 issue of the journal *Nature*, that at least half of circulating blood platelets in mice actually originate in the lungs. The Network wanted to know if non-HPS lungs transplanted into those with HPS would create normal blood platelets. If this were the case, it could have implications for treating the bleeding of HPS post transplant. The research found that the bleeding disorder of HPS does persist after lung transplantation in humans.

HPS Network facilitates research at its annual conference

Blood and stool samples for five different protocols were collected within the span of two hours at the HPS Network 25th Annual Conference, held March 9 – 11 in Uniondale, N.Y.

"This project had several logistical challenges," says Valarie Friedman, RN and Medical Director of the HPS Network, "We were able to work with our members, and the researchers, to overcome those challenges and make this happen." People with HPS are visually impaired, and thus to ensure informed consent, consent forms needed to be produced in large print or read to potential participants. The second challenge was that the blood needed to be spun and frozen within a short time frame after collection.

Despite these challenges, 38 people submitted blood samples, four submitted stool samples, 96 tubes of blood were drawn and informed consent was obtained for all samples.

"How can I expect a cure if I don't do anything to help accomplish that goal?" says Jessica Maldonado, one of the research participants. "I'll do everything humanly possible to help the doctors, if not for me, then for those beautiful children in our HPS family."

Individualized Research Plans help those with HPS and researchers connect in a patient-centric way

The HPS Network was awarded a Patient Advocacy Leadership Award by Sanofi Genzyme to support the Network's "Individualized Research Plan" (IRP) project. To prepare for future recruitment into drug trials, the Network is working with its membership to develop individualized plans for research participation. The process helps to identify interest in research participation, provide information about current research participation opportunities and identify any barriers to participation as well as strategies to overcome them.

"To make research truly patient centered, we need to meet patients where they live and this program is meant to do just that. This support will allow us to increase our engagement and effectiveness as well as further perfect the Individualized Research Plan tool itself." says Donna Appell, Founder and CEO of the HPS Network

Meeting of the Minds

The HPS Network hosts an annual meeting of researchers working on Hermansky-Pudlak Syndrome that is co-located with our conference for families. The Meeting of the Minds, as we call it, gives researchers a chance to share information and look for ways to collaborate. This is a way to be sure scientific resources are strategically used to look for treatments, and someday, the cure. Meeting of the Minds had 40 attendees in 2018 including:

Souheil El-Chemaly, MD who is working on the critical role of angiotensin II type 1 receptor in HPS1 lung fibrosis from Brigham and Woman's Hospital Boston, MA

Yang Zhou, PhD, Assistant Professor of Molecular Microbiology & Immunology (Research) Division of Biology and Medicine, Brown University, RI, who is working on how Galectin-3 interacts with the CHI3L1 axis and contributes to HPS lung disease

Chen Han from the NIH, National Heart, Lung and Blood Institute, in Bethesda, MD

Athena Cavounidis from the lab of Professor Holm Uhlig at Oxford University, England who is working on HPS and inflammatory bowel disease by dissecting defective antimicrobial pathways

Edward M. Behrens, MD, Chief of the Division of Rheumatology and the Joseph Lee Hollander Chair in Pediatric Rheumatology at the Children's Hospital of Philadelphia, PA who is working on HPS1/4 connections to inflammasome activity and inflammatory bowel disease

Sara Haroutunian from the National Institutes of Health in Bethesda, MD, who is working on the alveolar macro phage phenotype in a HPS-2 murine model of pulmonary fibrosis

Susan H. Guttentag, MD, Professor of Pediatrics and Director, Division of Neonatology Vanderbilt University, TN who is working on AP-3-mediated trafficking in AT2 cells and new insights into proteostasis

Kostas Alysandratos, MD, PhD, a Pulmonary Postdoc Fellow, at Boston Regenerative Medicine, Boston University, Boston MA, who is working on induced pluripotent stem cells to model alveolar epithelial cell dysfunction

Bernadette R. Gochuico, MD, with the NHGRI/NIH HPS clinical research program at the National Institutes of Health in Bethesda, MD, is working on HPS1 CRISPR/Cas9 mouse model of pulmonary fibrosis

Christian Mueller, PhD Associate Professor, Dept. of Pediatrics and Horae Gene Therapy Center UMASS Medical Center, Worcester, MA, who is working on lung physiology of an HPS1 CRISPR/Cas9 mouse model

Resat Cinar, PhD, Staff Scientist at the National Institutes of Health, NIAAA in Bethesda, MD, who is working on preclinical efficacy studies with hybrid CB1R and iNOS inhibitor (MRI-1867) in bleomycin-induced PF in pale-ear mice and NCATS/NCATS/TRND program support on HPS-PF project

Lisa R. Young, MD, Associate Professor of Pediatrics, Medicine, Cell Biology Vanderbilt University, TN, who is working on HPS clinical research in the Rare Lung Diseases Consortium

Dong Chen, MD, PhD ,Mayo Clinic, Chair, Division of Hematopathology, MN, who is working on the current state of HPS laboratory testing in the U.S.

Jesse Roman, MD Pulmonologist, CEO of the Jane & Leonard Korman Respiratory Institute Thomas Jefferson University Hospitals, Philadelphia, PA, who is working on strategies for HPS clinical care and research in Puerto Rico

William Gahl, MD PhD, from the National Institutes of Health in Bethesda, MD, who has been the primary investigator for the HPS protocols at the NIH since the mid 1990s

Samuel Seward, MD, Site Chair, Dept. of Medicine, Mount Sinai West, Mount Sinai St. Luke's and Prof. Medicine, General Internal Medicine, and who has served the HPS community as a physician for nearly 20 years.

Louis Cohen MD, Assist. Prof. Gastroenterology Mount Sinai, NY, who is working on GI research and HPS

Karen Amlani, Dr. Cohen's research assistant Mount Sinai, NY

Wilfredo De Jesús Rojas, MD Pediatric Pulmonary, San Juan

David Lederer, MD, MS New York Presbyterian Hospital/Columbia University Medical Center, NY

May Christine V Malicdan, MD Staff Scientist National Human Genome Research Institute and NIH Undiagnosed Program, Bethesda, MD

Melissa A. Merideth, MD Obstetrician and Gynecologist and Geneticist National Institutes of Health, MD

Enid Rivera, MD Professor and Director Hematology/Oncology Section Department of Pediatrics School of Medicine University of Puerto Rico

Kevin O'Brien, RN, MS-CRNP Adult Nurse Practitioner National Human Genome Research Institute (NHGRI) in Bethesda, MD

Anish Sharda, MD Beth Israel Deaconess Medical Center, Boston, MA

Maahika Srinivasan, PhD Clinical Research Assistant at Columbia University Medical Center, NY

Rosa I Roman Carlo, MD Pulmonary Fibrosis Clinic Mayaguez Medical Center Mayaguez, PR

Alexandros Strikoudis, PhD Postdoctoral Research Scientist Columbia University Medical Center, NY

Keith Sultan, MD Gastroenterology Northwell Health, NY

Ross Summer, MD Critical Care/ Pulmonary Thomas Jefferson University, PA

Marina Zieger, PhD Post Doctoral Associate UMass Medical School Worcester, MA

Daniel Dilling, MD Medical Director Respiratory Care Loyola University

Malliga Iyer, PhD Staff Scientist, National Institutes of Health, NIAAA, MD

Judith Kelsen, MD Program Director of the Very Early Onset Inflammatory Bowel Disease Children's Hospital of Philadelphia, PA

Damien Kudela, PhD Founder and CEO of Cayuga Biotec, CA

George Kunos, M.D., Ph.D. Scientific Director Lab of Physiologic Studies, Section of Neuroendocrinology, NIAAA, MD

HPS Network attends Rare Lung Disease Consortium Conference

A delegation from the HPS Network attended the Rare Lung Disease Consortium Conference in Cincinnati in Sept, 2018. The HPS Network, as well as several of our researchers, are part of the Rare Lung Disease Consortium (RLDC) and as such receive funding for HPS research.

The RLDC is collaboration among patient organizations, clinical investigators and the National Institutes of Health (NIH). Its mission is to conduct pathway-driven clinical research, develop therapies for rare lung diseases and provide information about rare lung diseases to the patient and medical communities.

Ashley Appell and Yanelis Rivera Velez sang at the event that was held at the same location and time as the LAMposium, another rare disease group's conference. Their fantastic performance was great exposure for Hermansky-Pudlak Syndrome.

The HPS team included: Donna Appell, Sandra Ocasio, Brenda Rivera Velez, Ashley Appell, Carmen Camacho, Nancy Lee and Yanelis Rivera Velez.

HPS Network convenes meeting to accelerate gene therapy research

The HPS Network brought together eminent geneticists and other pulmonary researchers in December to discuss gene therapy for Hermansky-Pudlak Syndrome (HPS) and identify the work that must be done to accelerate research on this potential therapy. HPS presents several unique challenges to achieve a potential therapy. The researchers discussed and debated each of them and then divided up the questions that need to be answered to move forward. They will reconvene in March to discuss their progress and strategize how to move forward. **Among just some of the questions that must be answered are: ……….**

- What cell type is the correct target for a gene therapy?
- How will the gene therapy be delivered to that specific type of cell?
- Which gene correction methods would best apply to HPS?
- What animal models would be most ideal?
- How a potential clinical trial should be structured and how would the effectiveness of a potential therapy be measured.

The researchers that gathered for this inaugural meeting included:

John Douglas Burke, National Human Genome Research Institute

James Dahlman, PhD Principle Investigator, Dahlman Laboratory; Assistant Professor, Georgia Institute of Technology; Assistant Professor, Emory University Medical School

William Gahl, MD, PhD Clinical Director, National Human Genome Research Institute; NIH Director, Undiagnosed Disease Program; Senior Investigator, Medical Genetics Branch; Head, Human Biochemical Genetics Section; Principle Investigator, William Gahl Laboratory

Bernadette Gochuico, MD Principal Investigator, Clinical Protocols focusing on the Pulmonary Fibrosis of HPS; Attending Pulmonologist, National Human Genome Research Institute, NIH

Richard Hess,, PhD Biologist, Human Biochemical Genetics Member, National Human Genome Research Institute, NIH

Marjan Huizing,, PhD Scientist, Medical Genetics Branch, National Human Genome Research Institute, NIH

Donald Kohn MD PhD Professor, University of California at Los Angeles; Director, UCLA Human Gene Medicine Program; Co-Leader, Center for Translational Technologies; Principle Investigator, Kohn Laboratory

May Malicdan, MD, PhD Staff Scientist, National Human Genome Research Institute; Staff, William Gahl Laboratory; Undiagnosed Diseases Program, NIH

Christian Mueller, PhD Associate Professor, University of Massachusetts School of Medicine; Principle Investigator, Mueller Laboratory for Gene Therapy; Chief Scientific Officer and Co-Founder, Apic Bio, Inc.

Samuel Seward, MD, FAAP, FACP Professor and Chair, Department of Medicine, Mount Sinai St. Luke's and Mount Sinai West Hospital, New York City

Cynthia Tifft, MD, PhD Deputy Clinical Director, National Human Genome Research Institute; Director, Pediatric Undiagnosed Diseases Program; Associate Investigator, Medical Genetics Branch, NIH

Bruce Trapnell, MD PhD Director, Transitional Pulmonary Science Center; Assistant Director, Adult Cystic Fibrosis Care Center; Professor, University of Cincinnati; Attending Physician, Cincinnati Children's Hospital; Scientific Director, Pulmonary Alveolar Proteinosis Foundation; Principle Investigator, Bruce C. Trapnell Laboratory

Lisa Young, MD Principle Investigator, Lisa R. Young Laboratory; Associate professor, Pediatrics, Medicine and Cell and Developmental Biology; Chair in Pediatrics, Vanderbilt University; Director of Research, Division of Pediatric Pulmonary Medicine ; Director, Pediatric Rare Lung Diseases Clinic and Adult Rare Diseases Clinic

Marina Zieger, PhD Postdoctoral Associate, Mueller Laboratory for Gene Therapy, University of Mass School of Medicine

Outreach

Outreach for the HPS Network include activities aimed at both patients and the medical community. We present and host community events as well as attending medical meetings.

American Thoracic Society

Team HPS attends American Thoracic Society International Conference

A team from the HPS Network attended the 114th American Thoracic Society International Conference in San Diego in May to hear the latest in pulmonary research, and to generate awareness of Hermansky-Pudlak Syndrome (HPS). More than 116,000 pulmonary doctors, researchers, nurses and therapists from 102 countries attended the conference.

The HPS Network manned a booth on the exhibition floor to generate awareness, provide literature to interested doctors and researchers and to answer questions. Volunteers with HPS in the booth showed off their eyes to demonstrate what nystagmus looks like and showed photos of various members to illustrate the varying skin tones in our community.

While some of the team manned the booth, others attended scientific meetings to hear the latest in pulmonary fibrosis research and keep an eye out for developments that might be applicable to those with HPS one day.

Carmen Camacho, a member of the HPS Network's board of directors, gave a presentation about the benefits of palliative care for patients in one of the conference's sessions. "Pallative care isn't just for people who are dying. It isn't the same as hospice. More patients could benefit earlier in the course of their disease," says Camacho.

The HPS Network also hosted a chocolate reception at The Melting Pot for HPS researchers and physicians. It is a tradition the Network started several years ago and provides a chance for interested doctors and researchers to network informally in a relaxed atmosphere. It also gives them a chance to connect in person in between the Meeting of the Minds, a research meeting held in conjunction with the HPS Network Conference.

This year's team attending ATS included: Carmen Camacho, Nancy Lee, Donna Appell, Ashley Appell, Demetria Saffore, Kristen Brantner, Candice Sipe and Crystal Sipe.

HPS Network exhibits at NY Thoracic Society

The HPS Network exhibited at the annual meeting of the New York Thoracic Society, held March 23-24, 2018 at the Westchester Medical Center in Valhalla, N.Y. Exhibiting at this event gives the HPS Network a chance to reach out to pulmonologists in New York to increase awareness of HPS, and to make them aware of the services the HPS Network can offer their patients. "It's an honor to be at this event, and to support the New York Thoracic Society in any way we can," says Donna Appell, Executive Director and Founder of the HPS Network. Donna, and her daughter Ashley Appell, manned the HPS booth at the event.

HPS Network Supports the 2018 FASEB Science Research Conference on "The Lung Epithelium in Health and Disease"

The HPS Network) donated $5,000 to the 2018 Federation of American Societies for Experimental Biology (FASEB) Science Research Conference on "The Lung Epithelium in Health and Disease." The FASEB conference was held, July 29 – August 3, 2018 in Olean, NY. Understanding the lung epithelium better will help not only patients with Hermansky-Pudlak Syndrome, but those with other lung diseases as well. This work is vital to discoveries that will, hopefully, lead to better treatments, and someday cures.

HPS Network Donates Funds to Support Pediatric HPS Clinic in Puerto Rico

The HPS Network donated $1,000 to support the efforts of Dr. Enid Rivera and Dr. Wilfredo De Jesus Rojas to provide a pediatric clinic for children with Hermansky-Pudlak Syndrome in Puerto Rico. The funds went to purchase a spirometer, mouth pieces and nose clips for the clinic. Dr. Rojas is interested in exploring the pulmonary function of children with HPS to see if there is anything we can learn to identify lung disease early.

The clinic is held the third Thursday of each month at the University of Puerto Rico Medical Sciences Campus, Pediatric Hospital in San Juan. The equipment will also be used at a satellite clinic at Mayaguez Medical Center every four months.

Puerto Rico Clinics: AMAZING YEAR!

HILDA ON THE ROAD

So much has been done this year advancing the healthcare of individuals with HPS on the island of Puerto Rico! Many thanks to Dr. Jesse Roman and Dr. Rosa Roman who have continued there work with the Pulmonary Fibrosis Clinics in Mayaguez and Dr. Enid Rivera and Dr. Wilfredo De Jesus Rojas founding and expanding the children's clinic in San Juan. Our wheels on the ground, Hilda Cardona RN (member of the HPS Network Board of Directors), with her many people affected by HPS on the island, have been busy representing the HPS Network at a number of events in Puerto Rico. Among them:

Asthma Coalition Clinics

7th Respiratory Congress and first Pulmonary Hypertension Summit in PR

Annual Convention of Pediatrics West Puerto Rico AMPRO

Asthma Coalition meeting

Hematology and Oncology Conference

Family Health Fair at the Ponce Plaza del Caribe

HPS Network Inc. | *Trying to find a cure with every breath!*

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2018 Board of Directors

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Heather Kirkwood
Carmen Camacho LSW
Nancy Lee
Hilda Cardona RN
Becky Nieves
Kristen Brantner
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Richard Appell

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Dr. Bernadette Gochuico
Dr. Lisa Young

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