

2025



# IMPACT REPORT

## *Support that makes a real difference*



### **A letter from Executive Director Donna Appell:**

Each year, we look back with gratitude for all that we've accomplished and all of it is because of you. Your generosity has helped the HPS Network continue to bring hope, education, and connection to families facing Hermansky-Pudlak syndrome. You have helped us keep our researchers engaged, our families supported, and our community strong. But the truth is, the funding that sustains this vital work is never guaranteed. Grants and research dollars fluctuate from year to year, and yet the needs of our families never stop. Every day, we answer calls from newly diagnosed families, help patients find medical specialists, guide researchers who are searching for answers, and bring people together who thought they were alone. These efforts from our clinics and conferences to our family outreach and research collaborations exist only because of you.

Now, more than ever, we need your help to keep the needle moving to ensure that no family feels forgotten, and that our researchers can continue their life-changing work. Please consider renewing your support today. Every gift, large or small, helps us continue to bridge the gap between science and compassion and to make sure that together, we never lose sight of hope.

With heartfelt gratitude,

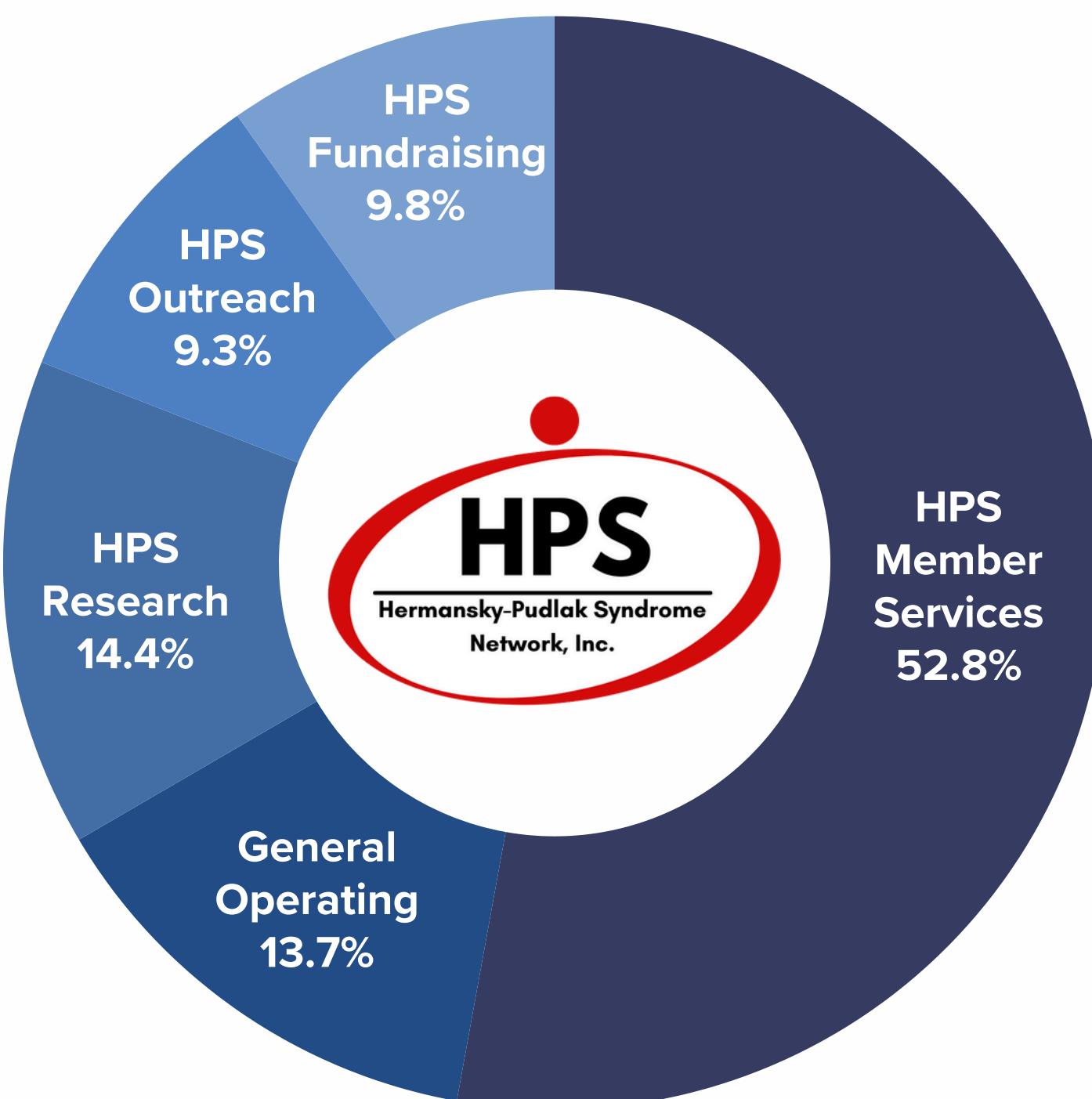


HPS Network, Inc.

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# How funding was spent this year to support the HPS community



## HPS Outreach

- American Thoracic Society Conference
- HPS presentations at academic and professional venues
- Support of global scientific conferences relevant to HPS

## HPS Research

- American Thoracic Society Partnership Research Grant
- NIH Research
- Meeting of the Minds
- Albinism International Databank
- “We’re Drawn Together” specimen collection program

## HPS Member Services

- New Member Welcome and Information Packets
- New Member Orientation
- Care Management Guidance
- Assistance with accurate diagnosis
- Member outreach training
- New York Conference
- Family Education Day in Puerto Rico
- Multidisciplinary Clinics in Puerto Rico
- Monthly Member Calls & Town Hall
- Physician and Researcher Continuing Education in PR
- Advocacy work to support vital policies
- TIPS (Transplant Information & Peer Support) Program
- Virtual support forums and more...

# A few Network Highlights:

- Leadership team meetings are held several times a week
- Town Hall Meetings are held monthly to give updates to all members and caregivers
- Peer Support Calls are held 5 per month in both Spanish and English, facilitated by a social worker
- Family Conference in New York
- Research workshop “Meeting of the Minds”
- Family Education Day in Puerto Rico
- Puerto Rico Continuing Medical Education
- Multidisciplinary HPS Clinics held every 3-4 months in Puerto Rico, Each clinic services 30-40 patients / 8+ sub-specialists in attendance
- Hosted first Research Meeting in Puerto Rico
- American Thoracic Society (ATS) Annual Conference attendance included: HPS Educational Exhibit, Patient & Expert Forum, networking and hosted research reception, Donna is Chair of the Public Advisory Roundtable (PAR) and a member of the ATS Board of Directors
- HPS presentations: Conference on CRC and Clinical trials in Japan, Columbia School of Medicine presentation to medical and dental students/residents, International Scientific Conference on Albinism, Rare Disease Day
- HPS Network was the recipient of the Abbey S. Meyers Leadership Award from the National Organization for Rare Disorder (a NORD Rare Impact Award)
- Recipient of the NIH Community Champions for Disability Health Challenge Funding Award
- Welcomed new HPS Chief Medical Officer
- Hired a Clinical Care Coordinator in PR
- Hosted our first annual HPS 6-Minute Walk on April 6th
- Albinism International Databank (AID) creates a platform for participants around the world to strengthen their voices and share information about Albinism/HPS/CHS. Designed with the input of scientists and participants, this global resource will provide data for the researchers to help improve Albinism/HPS/CHS standards of care.



Learn more about the AID at [aid.iamrare.org](http://aid.iamrare.org)

Please look to see some of the work that your donations have helped support:

[www.youtube.com/@hpsnetwork](https://www.youtube.com/@hpsnetwork)

Use your phone camera to scan these QR codes, click the youtube link that appears to watch the videos now!



## HPS in U.S. Mainland



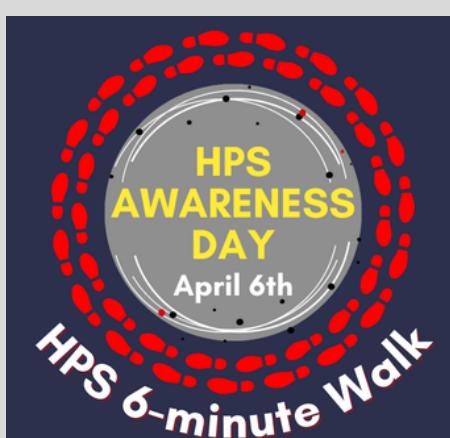
## HPS in Puerto Rico



## HPS at ATS



Save the Date: On April 6th, join the HPS community in our virtual 6-minute walk to help raise awareness for the Hermansky-Pudlak Syndrome Network



We are so grateful for the previous support of all of the important work being done, but we humbly ask for your continued generosity to help us reach our ongoing goals to:

- Host the annual HPS Family Conferences in New York and Puerto Rico
- Support HPS Research at the NIH
- Fund the American Thoracic Society Partnership Research Grant
- Increase infrastructure in Puerto Rico to better serve the HPS population on the island
- Support HPS member services to improve the quality of life for those impacted by HPS