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Senator Jamie Barlucea Rodriguez
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El Capitolio
San Juan, Puerto Rico 00901

Re: P. del S. 1386 – Request to Preserve and Incorporate the Strong Protections Established by P. del S. 247 / Law 109-2022

Dear Senator Jamie Barlucea Rodriguez,

I am writing to express my support for the effort to establish a comprehensive law protecting the rights, health, education, employment, and dignity of people with **Albinism and Hermansky-Pudlak Syndrome (HPS)** in Puerto Rico.

The proposed **P. del S. 1386** represents an important opportunity to strengthen protections for this community. I particularly appreciate its recognition of the human rights of people with albinism and HPS, its attention to discrimination and reasonable accommodations, its provisions regarding education and employment, its emphasis on data collection and research, and its creation of an interagency mechanism to coordinate public policy.

At the same time, I respectfully ask the Legislature to **preserve and incorporate into P. del S. 1386 the strongest healthcare protections established through P. del S. 247 and Law 109-2022**.

The objective should not be to choose between the two approaches. Rather, the new legislation can build upon the protections already established and expand them to address the broader needs of our community.

1. Preserve direct access to specialists without a referral

P. del S. 247 recognized the importance of **direct access to healthcare providers and medical specialists without requiring a prior referral**.

P. del S. 1386 contains similar language in Article 4(a), which is an important protection that should remain in the final law.

For people with rare diseases, unnecessary referral requirements can create delays in diagnosis, treatment, and monitoring. Patients and their families should not have to

overcome additional administrative barriers simply to reach professionals with the expertise necessary to manage their condition.

2. Maintain comprehensive access to medically necessary treatment

P. del S. 247 specifically addressed access to **medications, treatments, therapies, and diagnostic tests that are scientifically validated and recommended for the condition**.

I respectfully request that this protection remain clearly stated in the new law.

The language should ensure that individuals with albinism and HPS have access to medically necessary care throughout the continuum of their lives—not merely at the time of diagnosis.

3. Explicitly recognize the multisystem nature of HPS

This is especially important for individuals with Hermansky-Pudlak Syndrome.

HPS should not be treated simply as a form of albinism involving pigmentation and vision. It is a rare genetic disorder that can involve multiple organ systems and may require lifelong monitoring and specialized care.

P. del S. 1386 appropriately identifies **hematology, pulmonology, gastroenterology, and <u>medical genetics for DNA diagnosis</u>** in Article 4(d).

I respectfully request that these specific specialties remain in the final legislation and that the law clearly recognize that other specialists and subspecialists may also be necessary depending on the individual's clinical needs.

4. Strengthen pulmonary protections for HPS

For individuals with HPS who develop pulmonary complications, (pulmonary fibrosis), access to specialized pulmonary care can be critical.

The new legislation should preserve the explicit reference to **pulmonology** and ensure access to appropriate evaluation, monitoring, diagnostic testing, treatment, and follow-up when clinically indicated.

The legislation should also recognize that HPS pulmonary fibrosis is progressive and that appropriate surveillance is an essential component of preventive care.

5. Preserve hematology protections

P. del S. 1386 appropriately identifies hematology as a specialty for individuals with HPS.

This protection should be maintained because the bleeding disorder associated with HPS can significantly affect medical procedures, surgeries, dental procedures, pregnancy, trauma, and other aspects of healthcare.

Access to HPS expert hematologists who understand HPS should therefore be considered an essential component of comprehensive care.

6. Preserve specialized ophthalmologic and low-vision services

The previous legislation and P. del S. 1386 both recognize the importance of specialized eye care.

We respectfully request that the final law continue to specifically provide for:

- Specialized ophthalmologic evaluation and follow-up;
- Low-vision services;
- Optical aids;
- Assistive technology;
- Appropriate visual rehabilitation; and
- Other medically necessary services related to visual impairment.

These services are fundamental to education, employment, independence, mobility, and quality of life.

7. Preserve dermatologic care and prevention of skin cancer

The provisions of P. del S. 1386 addressing dermatological evaluation, prevention, early detection, and treatment of precancerous lesions and skin cancer are extremely important and should remain in the final law.

People with albinism have a particular need for lifelong education, prevention, surveillance, and treatment related to ultraviolet exposure.

8. Recognize sunscreen and sun protection as medically necessary

One important aspect of the previous legislation was its recognition of sun protection as part of the healthcare needs of people with albinism.

I respectfully request that P. del S. 1386 make this protection **explicit and enforceable**, including appropriate access to medically necessary sunscreen and other sun-protective measures when clinically indicated. This is very important for those with HPS because they cannot receive the vitally necessary lung transplant with a skin cancer diagnosis.

Sunscreen should not be treated merely as a cosmetic product. In the appropriate circumstances, it is part of preventive healthcare.

9. Preserve genetic testing and early identification of HPS

The previous legislation recognized the importance of identifying HPS within Puerto Rico's surveillance system.

P. del S. 1386 should preserve and strengthen provisions that facilitate appropriate **genetic evaluation and testing** of all individuals with albinism. Facilitating the identification of which individuals with albinism have one of the 11 HPS subtypes is necessary to design the proper plan of care.

Early identification can allow patients and healthcare professionals to establish appropriate monitoring and take precautions related to bleeding and other potential complications.

10. Maintain surveillance and accurate data collection

P. del S. 1386 contains important provisions regarding data collection and surveillance.

These provisions should be retained and implemented in a way that allows Puerto Rico to understand:

- How many individuals are affected;
- Which HPS and albinism subtypes are present;
- Where patients are located;
- Their access to medical specialists;
- Their access to dermatology and ophthalmology;
- Their access to sunscreen and other necessary resources;
- Major medical complications; and
- Healthcare utilization and outcomes.

Accurate information is essential for planning services, allocating resources, supporting research, and evaluating whether the law is actually improving patient outcomes.

11. Preserve meaningful insurance protections

P. del S. 247 established important responsibilities involving **ASES and health insurance coverage**.

P. del S. 1386 should preserve and strengthen those protections.

The final law should clearly establish that medically necessary evaluation, diagnosis, treatment, follow-up, rehabilitation, visual aids, and other appropriate services for albinism and HPS are covered when medically indicated.

It should also provide meaningful mechanisms for enforcement when coverage is denied.

12. Preserve protections for individuals who cannot afford private care

Individuals with rare diseases should not lose access to specialized care because of financial circumstances.

The final legislation should ensure that individuals who are medically indigent or otherwise unable to obtain appropriate care through private insurance have meaningful access to the services established by law. Those with severe HPS manifestations should be by Catastrophic Coverage

13. Continue collaboration with the University of Puerto Rico Medical Sciences Campus

P. del S. 247 recognized the importance of collaboration with the **University of Puerto Rico Medical Sciences Campus**.

P. del S. 1386 already creates an important role for the Medical Sciences Campus through the Interagency Committee.

I respectfully ask that the Interagency Committee focus on strengthening relationships throughout Puerto Rico and promote:

- Specialized training;
- Clinical expertise;
- Research;
- Professional education;
- Development of protocols;
- Telehealth or consultation opportunities where appropriate; and
- Improved access to specialists for patients throughout Puerto Rico.

14. Preserve education and awareness

I strongly support the educational and awareness provisions contained in P. del S. 1386.

Education is necessary not only for the public but also for healthcare professionals, educators, employers, and government personnel.

For the education of those with albinism/HPS accommodations should be provided.

People with albinism and HPS should not repeatedly have to explain their medical condition to every provider, teacher, employer, or government agency they encounter.

15. Maintain June 13 as an important day of awareness

The recognition of **June 13 as International Albinism Awareness Day** should remain part of the legislation.

This provides an important opportunity to educate the public about albinism and HPS, combat myths and stigma, promote human rights, and highlight the importance of medical care and inclusion.

A REQUEST TO BUILD, NOT REPLACE

The purpose of this request is not to diminish the importance of P. del S. 1386.

Rather, it is to ensure that the new legislation **builds upon the protections that Puerto Rico has already established**.

P. del S. 1386 contains important new protections related to:

- Human rights;
- Government nondiscrimination;
- Reasonable accommodations;
- Inclusive education;
- Employment;
- Data collection;
- Research;
- Interagency coordination; and
- Public awareness.

These protections should be maintained.

At the same time, the specific healthcare protections established under P. del S. 247/Law 109-2022 should not be lost in the process of creating the new law.

Our request is simple:

Keep the protections that have worked.
Strengthen the protections that are needed.
Add the new protections contained in P. del S. 1386.
And ensure that no essential healthcare protection is lost.

A truly comprehensive law should address both the **rights** and the **medical realities** of people living with albinism and HPS.

For someone living with HPS, access to a knowledgeable hematologist or pulmonologist is not simply an issue of convenience. Appropriate medical care can be essential to preventing complications, safely undergoing medical procedures, monitoring disease progression, and maintaining quality of life.

Likewise, for all persons with albinism, access to low-vision services, appropriate ophthalmologic care, dermatologic surveillance, and adequate sun protection can directly affect their ability to study, work, participate in their community, and live independently.

We therefore respectfully ask the Senate of Puerto Rico to review the protections established through **P. del S. 247/Law 109-2022** and incorporate those protections into the final version of **P. del S. 1386**, while retaining the broader human rights, educational, employment, research, and social protections proposed in the new legislation.

The result can be a comprehensive law that protects the **whole person**—their health, education, employment, independence, dignity, and fundamental human rights.

Thank you for your consideration and for your commitment to the individuals and families living with albinism and Hermansky-Pudlak Syndrome in Puerto Rico.

Respectfully,

Donna Appell, RN
Executive Director and Founder
HPS Network, Inc.

Carmen Camacho, MA, LSW
Rare Disease Patient Advocate for the
Hermansky-Pudlak Syndrome Community
HPS Network, Inc. Board Member

Hilda Cardona, RN
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