



8th Annual Conference

Sponsorship Opportunities

Chicago, Illinois, USA

June 21-23, 2024

What is PURA syndrome?

PURA Syndrome is a rare genetic disorder that affects neurodevelopment. It was first described in medical literature in October of 2014. The PURA gene is on the 5th chromosome. It has a number of different roles, but is known to be particularly important in brain development. This is why problems with the PURA gene are primarily associated with a neurodevelopmental disorder.

To date, the PURA Syndrome Foundation is aware of just over 600 individuals with PURA Syndrome worldwide. However, given that modern genomic tests are becoming cheaper and more widely accessible, it is likely that hundreds more people will be diagnosed with PURA syndrome in the next few years.

Almost all patients with PURA syndrome are non-verbal and have various motor difficulties, including challenges with walking or an inability to walk independently. Children have a variety of neurological symptoms from birth. This includes trouble breathing, maintaining body temperature, severe sleepiness, feeding difficulties and very low muscle tone (hypotonia). Many patients experience seizures or seizure-like episodes.

What is the PURA Syndrome Foundation?

The PURA Syndrome Foundation is a global organization, registered in the USA as a 501(c)(3) tax-exempt non-profit corporation. The PURA Syndrome Foundation supports and educates patients and their families, providing a global community. This community provides a place of belonging to those who may otherwise feel isolated by rare disease, enriches the medical research being completed and educates those outside the community about the condition.

Our mission is to support and drive research, raise awareness in the general community, as well as connect, educate, serve, and empower families impacted by PURA Syndrome. Our biggest annual event is a conference where the families of patients with PURA syndrome can convene, support each other and share resources. They also meet with and hear from, medical researchers who are working to understand PURA syndrome. Bringing the families and researchers together at this event, increases understanding and knowledge for research. This in turn, enhances the quality of life for patients and their families.

How can you help?

We are in need of sponsors to support our annual conference. In supporting this conference, you provide our global medical team the chance to come together and make plans for future research, to benefit PURA syndrome patients. All donations and support are much appreciated. Funds will go directly to funding our annual conference. Your sponsorship is a wonderful way to show your support to families living with this rare disease. With your help, there is much hope for the future.

Sponsorship Levels, Prices and Benefits of Sponsorship

(all prices are listed in USD)

All materials subject to approval by PURA Foundation board. Please submit to conference@pura-syndrome.org. Response will be given within 2 weeks of receiving items.

PURA PLATINUM SPONSOR - \$8,000 (1 spot available)

- ❖ Recognition as the premium sponsor of the conference.
- ❖ Sponsorship recognition (full page ad space) in all printed and electronic conference materials.
- ❖ Recognition in all press releases.
- ❖ Logo & recognition on the PURA Conference website and social media pages.
- ❖ Podium address and recognition at Saturday dinner event.
- ❖ Conference room signage. (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Product demonstration, product samples, giveaways or fliers distributed to attendees (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Recognition in the email messages sent to attendees.

PURA GOLD SPONSOR - \$5,000

- ❖ Sponsorship recognition (full page ad space) in all printed and electronic conference materials.
- ❖ Recognition in all press releases.
- ❖ Logo & recognition on the PURA Conference website and social media pages.
- ❖ Conference room signage. (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Product demonstration, product samples, giveaways or fliers distributed to attendees (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Recognition in the email messages sent to attendees.

PURA SILVER SPONSOR - \$2,000

- ❖ Sponsorship recognition (half page ad space) in all printed and electronic conference materials.
- ❖ Recognition in all press releases.
- ❖ Logo & recognition on the PURA Conference website and social media pages.
- ❖ Conference room signage. (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)

- ❖ Product demonstration, product samples, giveaways or fliers distributed to attendees (provided by you and mailed your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Recognition in the email messages sent to attendees.

PURA BRONZE SPONSOR - \$1,000 (unlimited spots available)

- ❖ Sponsorship recognition (quarter page ad space) in all printed and electronic conference materials.
- ❖ Recognition in all press releases.
- ❖ Logo & recognition on the PURA Conference website and social media pages.
- ❖ Conference room signage. (provided by you and mailed to your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Product demonstration, product samples, giveaways or fliers distributed to attendees (provided by you and mailed your sponsor contact, if not attending. Address will be provided once approved.)
- ❖ Recognition in the email messages sent to attendees.

PRINTED PROGRAM ADS

A great way to advertise your product or service, or recognize a particular family and/or child.

- ❖ Printed Program Ad \$150 Full page
- ❖ Printed Program Ad \$100 Half page
- ❖ Printed Program Ad \$50 Quarter page

Please send completed form, materials, or questions to: conference@pura-syndrome.org

Once approved, payment/checks will be made to: PURA Syndrome Foundation.

In memo section, please write Annual Global PURA conference

Mail to:

PURA Syndrome Foundation
c/o Damon Fisher
PURA Foundation Board Treasurer
129 Shelf Rock Road
Driftwood, TX 78619
USA

Thank you for your support

PURA FOUNDATION CONFERENCE SPONSOR FORM

*please be sure to attach ad you want displayed

Type of Sponsorship: _____

Name of Organization: _____

Contact Person: _____

Mailing Address: _____

Phone Contact: _____

Email: _____

Website: _____

Specify Name of Company/Family/or child to be recognized in ad:
