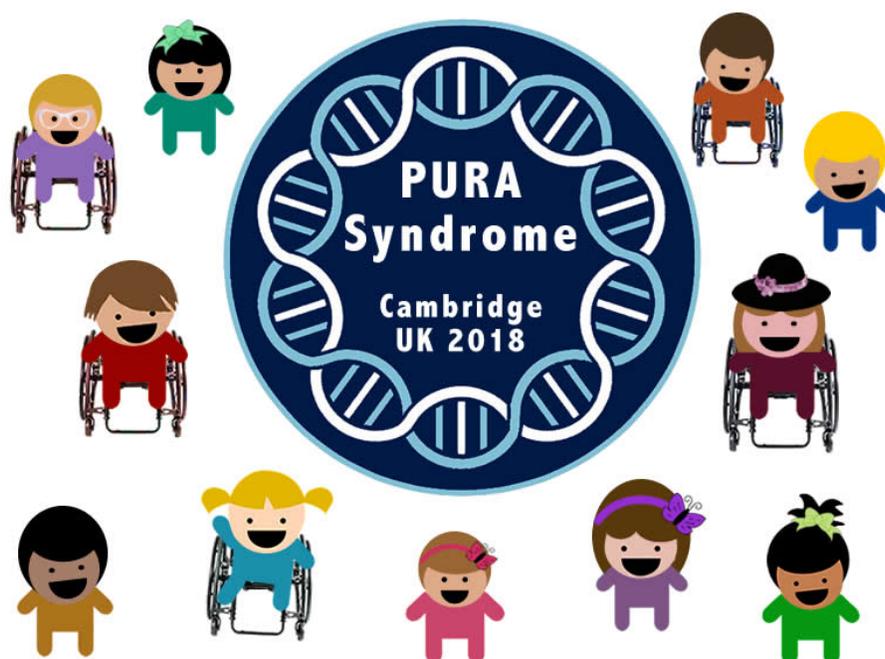




PURA Syndrome Foundation

3rd Annual Global Conference

**Wellcome Genome Campus Conference Centre
Cambridge UK - June 2018**



Sponsorship Opportunities

www.purasynndrome.org



Thank you for your interest in the PURA Syndrome Foundation

What is PURA syndrome?

PURA syndrome is a rare condition, first described in medical literature in 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.



Currently, there are approximately 180 confirmed cases of PURA syndrome globally, with 30 known cases diagnosed via the UK medical community and the DDD study. Our identified numbers have approximately doubled each year, and are expected to continue to do so for the foreseeable future. The age of patients globally ranges from 3 months to 30 years. Patients with PURA syndrome are essentially non-verbal, with 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 charitable organisation. The 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 serve, educate and help fund research for families coping with the effects of 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 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?

Given the relatively new awareness of PURA syndrome and the formation of the PURA Syndrome Foundation, we are in need of sponsors to support our 3rd 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 and/or our medical research grants. With your help, there is much hope for the future.



Conference Venue and Date



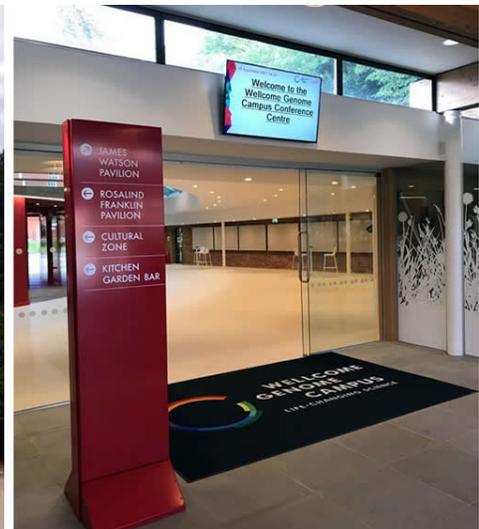
**WELLCOME
GENOME
CAMPUS**

**CONFERENCE
CENTRE**

The Wellcome Genome Campus is home to some of the world's foremost Institutes and organisations in genomics and computational biology, committed to delivering life-changing science with the reach, scale and imagination to solve some of humanity's greatest challenges. The Conference Centre is a beautiful complex within the Hinxton Hall Estate and its 100-acre parkland bordering the river Cam, just outside Cambridge UK.

The PURA Syndrome Foundation 2018 conference will be held at the Wellcome Genome Campus over a 3 day period: Fri 22nd - Sun 24th June. The Friday is the medical research meeting day, where our Global Research Network meets to plan research for the condition. The Saturday and Sunday sessions provide clinicians and researchers a chance to update and educate families on research results and future work. In 2018 we will also be sharing our Global Patient Registry at the event.

The Conference Centre is an impressive modern space. Underneath the new glass roof lies a large, naturally-lit open venue and event area – ideal for informal discussion, networking, poster sessions and evening drinks – and the Campus Cultural Zone. Off the main area are two medium-large meeting rooms (Rosalind Franklin and James Watson Pavilions) that can be set up in a variety of layouts. The Conference Centre is part of Wellcome Genome Campus Connecting Science, providing meeting, networking and relaxation spaces conducive to learning and sharing.





Sponsorship Form - 3rd Annual PURA Syndrome Conference

Wellcome Genome Campus Conference Centre, Cambridge UK

22-24th June 2018

Name or Organization/Person: _____

Mailing Address: _____

Phone Contact: _____

Email: _____

Web address: _____

Sponsorship Levels, Prices and Benefits of Sponsorship

Opportunities range from £50 to £5000

CONFERENCE GOLD SPONSOR - £5000 – one only

- Sponsorship recognition on both the Wellcome Genome Campus Conference Centre registration webpage and the PURA Syndrome Foundation website
- Sponsorship recognition (full-page ad space) in all printed and electronic conference materials.
- Recognition in all press releases.
- Representation on the Foundation websites and social media pages.
- Four (4) guests to attend the conference day and Saturday night dinner.
- Product samples, giveaways or fliers distributed to attendees.

CONFERENCE DINNER SPONSOR - £3500 – one only

- Exclusive sponsorship of the main Saturday night dinner event.
- Sponsorship recognition on both the Wellcome Genome Campus Conference Centre registration webpage and the PURA Syndrome Foundation website
- Sponsorship recognition (half-page ad space) in all printed and electronic conference materials.
- Recognition in all press releases.
- Representation on the Foundation website and social media pages.
- Two (2) guests to attend the dinner.
- Product samples, giveaways or fliers distributed to attendees and placed on tables during dinner.
- Recognition in the email messages sent to attendees pre- and post-conference.



MEDICAL RESEARCH DAY SPONSOR - £2000 – one only

- Sponsorship recognition on both the Wellcome Genome Campus Conference Centre registration webpage and the PURA Syndrome Foundation website
- Sponsorship recognition (quarter-page ad space) in all printed and electronic conference materials.
- Recognition in all press releases.
- Representation on the Foundation website and social media pages.
- Product samples, giveaways or fliers distributed to researchers and general attendees.

SILVER SPONSOR - £1500

- Sponsorship recognition (half-page ad space) in all printed and electronic conference materials.
- Recognition in all press releases.
- Representation on the Foundation website and social media.
- One (2) guest to attend the conference day.
- Product samples, giveaways or fliers distributed to attendees.



BRONZE SPONSOR - £500

- Sponsorship recognition (quarter-page ad space) in all printed and electronic conference materials.
- Recognition in all press releases.
- One (1) guest to attend the conference.
- Representation on the Foundation website and social media.
- Product samples, giveaways or fliers distributed to attendees.

PRINTED PROGRAM ADVERTISEMENT

This is a great way to advertise your product or service, as well as a way to thank and recognize your PURA family.

- Printed Program Ad £150 Full-page program ad
- Printed Program Ad £100 Half-page program ad
- Printed Program Ad £50 Quarter-page program ad

**For sponsorship and/or questions, please contact our President
Dominic J. Spadafore**

e-mail d.spadafore@pura-syndrome.org