
DYRK1A Syndrome US & International Association

Annual Report

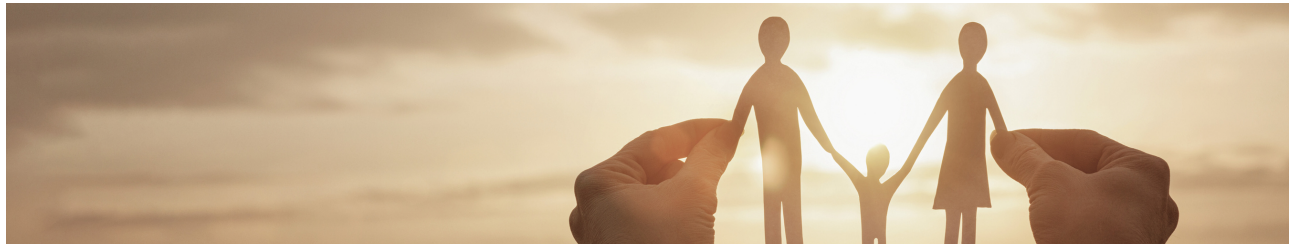
2023

700 FAMILIES STRONG



DYRK1A
Syndrome

www.dyrk1a.org / dsia@dyrk1a.org



Family Support and Information

DYRK1A Digest:

Our Monthly e-newsletter people informed about activities, stories, and research all around DYRK1A Syndrome.

DYRK1A Blog:

We've shared several blog stories on our website from families sharing their life experiences related to their child with DYRK1A Syndrome

Welcome Package:

Our welcome packet of information helps us embrace new families and provide them with a sense of community. The packet was viewed 6812 times on our website for the year. We've mailed welcome packages to 27 families; the package brings initial information that new families are eager for.

US Annual Family Meet-up:

We had a successful in-person family meet-up with 32 families and 140 people. We had a packed agenda with researchers, therapists, and families sharing their experiences. We ended our event with a fun-filled day visiting Denver Zoo on Sunday. We provided travel scholarships for several families to attend this annual event.



Awareness and Visibility

DYRK1A Awareness Day:

In August our awareness day brought a 21,000 views to our website. Our social media presence reached 11,000 people. Our Common Questions was viewed 975 times during the month. dyrk1a.org/commonquestions

Run a K for DYRK1A:

This was our fourth family fun run or walk that allows people to bring awareness of DYRK1A in their local communities. We had 115 individuals and 20 family groups formally participate and many more in other capacities.

Clinical Care and Research

Medical and Scientific Advisory Board:

Our Medical and Scientific Advisory Board is meeting regularly with key dyrk1a researchers and discussing the best action plan to advance research and care for DYRK1A Syndrome.

Request for Proposal:

A plan has been made to fund research grants related to DYRK1A Syndrome. A Request for Proposal was finalized by the end of the year.

Scientific Roundtable:

We held our first scientific roundtable during our Family Conference. We had three scientist present their work with us.



International Partnerships

Partnerships

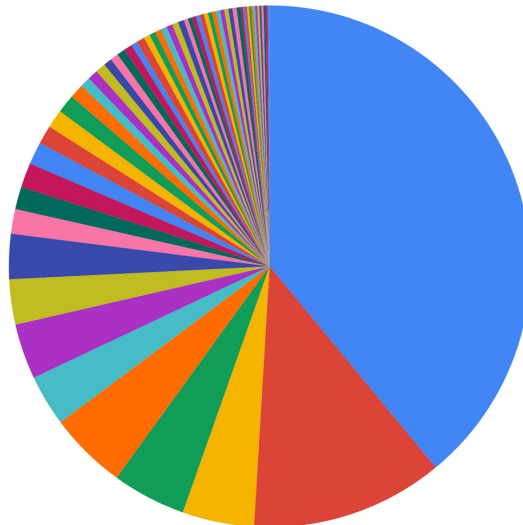
We continue to work on building our international partnerships. We have members and representatives all across the world. Our new welcome packet was created to be customized and shared with the international community.

Organizations

The Spanish Association of DYRK1A Syndrome held a conference, as well as the DYRK1A UK Community had a successful family meetup at The Wirral.

783 families from 61 Countries

- United States, United Kingdom, Canada, France, Germany, Netherlands, Australia, Spain, Italy
- Norway, Poland, Brazil, Ireland, Portugal, Belgium, Israel, Denmark, Finland, Sweden
- Malaysia, Mexico, Korea, New Zealand, Romania, Chile, Russia, Chile, Singapore, India
- Czech Republic, Moldova, Switzerland, Austria, Philippines, Croatia, Slovenia, Algeria, China
- Argentina, Puerto Rico, Morocco, Greece, Hungary, China, Japan, Kuwait, Turkey, Latvia
- Jamaica, Iraq, Namibia, Peru, Estonia, Cyprus, Serbia, United Arab Emirates, Bangladesh
- Pakistan, Paraguay, South Africa, Thailand





Finances

