

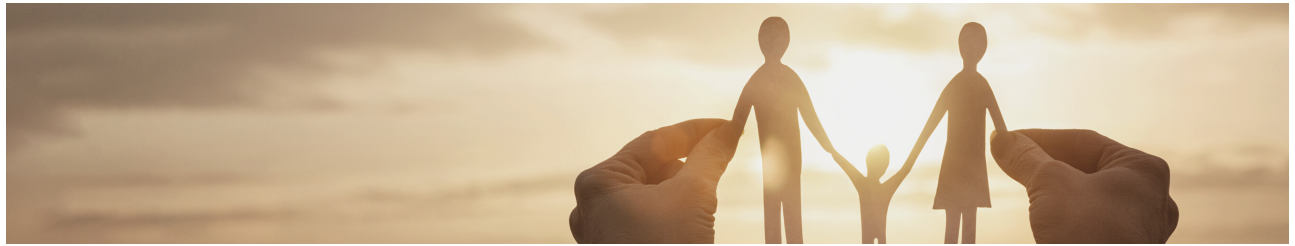
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DYRK1A Syndrome US & International Association

# Annual Report

2022





## Family Support and Information

### **DYRK1A Insight:**

In February we welcomed a speaker who covered Epilepsy; Identification and First-Aid.

### **DYRK1A Digest:**

Our Monthly e-newsletter is keeping 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:**

We created a welcome packet of information to embrace new families and provide them with a sense of community. The packet has been viewed 950 times on our website. We've mailed welcome packages to 26 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 150% increase in our website views. Our social media presence increased by more than 500% overall. We released a new resource, Common Questions, that was viewed 650 times during the month.  
[dyrk1a.org/commonquestions](http://dyrk1a.org/commonquestions)

### **Run a K for DYRK1A:**

This was our third family fun run or walk that allows people to bring awareness of DYRK1A in their local communities. We had 196 individuals and 23 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 will be released in early 2023.

### **Common Questions:**

Members of the Medical and Scientific Advisory Board helped answer Common Questions related to DYRK1A Syndrome that were put into the new resources.

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# International Partnerships

## Partnerships

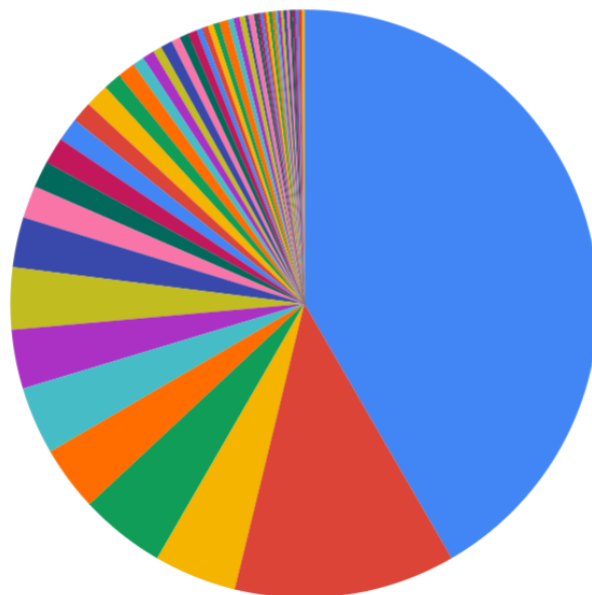
We continue to work on building our international partnerships. We have members and representatives all across the world. Our new welcome packet was created to be customized and shared with the international community.

## Organizations

Spain is the newest nonprofit organization, Spanish Association of DYRK1A Syndrome, [aesdyrk1a.org](http://aesdyrk1a.org). The DYRK1A UK Community had a successful family meetup at The Wirral.

### 630 families from 51 Countries

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





# Finances

