Jordan's Guardian Angels

Ambassador Program

As our global community continues to grow, our Ambassador Program aims to support families across regions and languages. All ambassadors are parent volunteers who have completed a special training to be best equipped in this role. Our ambassadors share a passion in connecting with our families and have shared experiences that can support other families on their journey.

Andrew Fruschien

Dad
English
USA - East Coast
CT, DE, FL, GA, ME, MD, MA, NH, NJ, NY, NC, PA, RI, SC, VT, VA, WV

Andrew lives in New Jersey with his wife Michelle, son Noah, princess Hailey (ppp2r5d), and their dog Bailey. Andrew works as a nurse practitioner in cardiology at Holy Name Medical Center in Teaneck, NJ as a healthcare worker. Andrew has always worked with his patients on creating a plan of care, however he now fully appreciates the complexity of the healthcare system being a parent of a child with Jordan's Syndrome. He remembers the first year before Hailey was diagnosed and some of the struggles his family had to endure. As a JGA Ambassador, he hopes to help other Jordan Syndrome families navigate the waters. He is extremely thankful for everything Jordan Guardian Angels offers and is proud to be a member of the team!

In his spare time, he enjoys spending time with his family, binging Netflix series with his wife, going to the beach, and being outdoors.

Jon and Stacy live in Ohio with their two daughters, Vivian and Brooklyn. At the age of 3, Vivian was the 40th individual diagnosed with the (then) newly discovered PPP2R5D gene variant. Until that point, Jon and Stacy had spent years searching for answers to her delays. As professionals in the medical field, it was challenging, frustrating, and disheartening that they could not identify the cause of her delays. Upon receiving her diagnosis, Jon and Stacy connected with Jordan's Guardian Angels and the other known families. That was life changing because they were able to talk to other families who understood the challenges and could answer their most burning questions. The connection and support from other families was crucial for their family. Jon and Stacy soon became passionate about advocating for their daughter, encouraging the other families affected by Jordan's Syndrome, supporting the ongoing research efforts, and being a resource for newly diagnosed families. Jon and Stacy feel blessed with unwavering support of family and friends, and they hope to extend that same support to others through the ambassador program.

Stacy and Jon Kelley

Mom and Dad
English
USA- Midwest
AL, AR, IL, IN, IA, KS, KY, LA, MI, MN, MS, MO, NE, ND, OH, OK, SD, TN, WI

Nancy DeOrta

Mom
English & Spanish
USA- Southwest
AZ, CO, NM, TX, UT

¡Hola! I"m Nancy and I live in Arizona along with my husband and our 3 spectacular kiddos. (Julian, Darian and Avianna) When we received Avianna's (ppp2r5d) diagnosis in 2015 not much information was available. I can remember the feeling when we first connected to our first family (Emma) all the way in New Zealand! The feeling of being able to connect with someone that understood everything that you are going through felt as if we finally found our place. We know how overwhelming receiving a diagnosis can be but please know that with finding our group you have now gained a global family. As an ambassador my hope is to provide support and guidance in this new journey.

¡Hola! Soy Nancy y vivo en Arizona con mi esposo y nuestros 3 niños espectaculares.(Julián,Darían y Avianna). Cuando recibimos el diagnóstico (PPP2R5D)de Avianna en 2015 no había mucha información. Me acuerdo como me sentía después de conectar con nuestra primera familia (Emma)que viven en Nueva Zelanda! La sensación de poder conectar con alguien que entiende todo por lo que estás pasando se sintió como si habíamos encontrado nuestro lugar. Sabémos lo abrumador que puede ser recibir un diagnóstico, pero ten en cuenta que al encontrar nuestro grupo ahora has ganado una familia global. Como embajadora, mi esperanza es proporcionar apoyo y orientación en este nuevo viaje.

I live in Washington State and am the parent to two boys. My oldest has Jordan's Syndrome and is 13 years old. He received his diagnosis at age 9. I was happy to get the diagnosis as we had been searching for answers since infancy. Advocacy has come hand in hand with parenting my child with complex disabilities. I have been involved with advocacy efforts at the school district level, local county level and state level for disability related issues. I have volunteered with the Epilepsy Foundation, Parent-to-Parent, as well as a Disability Leadership training program. I have also taught middle school students as a special education teacher. Some of my favorite pastimes include spending time outdoors at parks, forests, or beaches. I love to travel and explore new places. I am always up for a sunny destination as it is very cloudy and rainy where I live. I am excited to serve as an Ambassador for JGA as I enjoy connecting with other parents and sharing what I have learned in hopes it can help other families.

Sharon Eliott

Mom
English
USA- West Coast
AK, CA, HI, ID, MT, NV, OR, WA, WY

Tuncay Sipahi

Dad
Canada
English

My family is from Ottawa Ontario. My wife Berna and I have 3 kids Bertun 11 years, Aysu 6 years old and Beren 2 years old. We were really caught off guard when Beren was diagnosed with PPP2R5D in 2022. I remember getting the call and it was a really hard moment to grasp. In search of answers about PPP2R5D and how I can help my child, I came to learn about Jordan's Guardian Angels. This was very constructive moment for us to learn from the JGA team and other parents with the same disease. It was a great opportunity to dive into the resource center about the amazing research going on right now and more. Participating in the family conference for research was a great experience and great pathway to contribute a little bit to the research. I would like to support the journey JGA started and help new and existing families in our region while also learning from them. Hopefully, together we can help the journey as much possible.

Karina and her husband Ezequiel live in Argentina, South America. Karina works in International Relations. She is the mom of Sofia (8) and Felipe (4). They got the PPP2R5D diagnosis when Sophia was 5 years old. To date, they remain the only family with Jordan's Syndrome in their country. Karina feels the need to participate and support Jordan's Guardian Angels. The Ambassador program enables her to welcome new Spanish speaking families and create a safe space for them despite the distance.

Karina Keegan: Ella y su marido Ezequiel viven en Argentina, América del Sur. Estudió y trabaja en el área de Relaciones Internacionales. Es mamá de Sofia (8 años) y Felipe (4 años). Recibieron el diagnóstico de Sofia (PPP2R5D, variante E198K) cuando la nena tenía 5 años, hasta el momento son la única familia con este diagnóstico en su país. Karina siente la necesidad de ayudar de alguna forma a la Fundación, y cuando surgió la posibilidad de hacerlo a través de darle la bienvenida a nuevas familias que hablaran español, le dio la orportunidad, a pesar de la distancia, de poder participar.

Karina Keegan

Mom
Spanish Speaking Regions
Spanish

Tom Anghileri

Dad
UK
English

Hello! - I'm Tom, and I live near Cambridge, UK, with my wife Abby and our three boys, Austin, Sam and Asa. Austin was diagnosed with Jordan's Syndrome (PPP2R5D - Q211P) in 2018, when he was 3 - although our journey towards a diagnosis started when Austin was 3 months old, as he had a few issues from birth and wasn't meeting developmental milestones. Since joining the Facebook community, we've attended the JGA Family Conferences in San Francisco and New York, and I became a JGA ambassador in 2022. As well as being a PPP dad, I'm a lawyer, musician and classic car enthusiast. I look forward to welcoming new families to the group, and to supporting the UK families as best I can.

Luca Belloni is a strategic advisor for a group of companies. He lives in Italy with his wife Francesca and their two children, Tommaso (7) and Giorgio (5). Giorgio received his PPP2R5D diagnosis at the age of 2 through the whole exome sequencing. Through Jordan's Guardian Angels, the family was able to connect with the Jordan's Syndrome community- a community that is going through the same hardships and can help answer questions and share experiences. When the opportunity of becoming an Ambassador came along, Luca felt compelled to give back to a community that has supported him in so many ways. He is excited to be supporting the Italian Speaking families and helping break down language barriers.

Luca Belloni si occupa di consulenza per un gruppo di aziende. Vive in Italia con la moglie Francesca e due figli, Tommaso (7) e Giorgio (5). Giorgio ha ricevuto la diagnosi di PPP2R5D all'età di due anni, a seguito del sequenziamento dell'esoma. Tramite Jordan's Guardian Angels, la famiglia ha potuto entrare in contatto con la comunità della Sindrome di Jordan – un gruppo di persone che attraversano le medesime difficoltà, e possono aiutare rispondendo a domande e condividendo esperienze. Quando si è presentata l'opportunità di diventare Ambasciatore per l'Italia, Luca si è sentito in dovere di mettersi a disposizione per restituire qualcosa alla comunità che per prima ha molto aiutato lui e la sua famiglia. Luca è entusiasta di supportare in ogni modo le famiglie italiane e, ove necessario, ad aiutare a superare le barriere linguistiche.

Luca Belloni

Dad
Italian Speaking Regions
Italian

Laure Galvani

Mom
French Speaking Regions
French

Laure Galvani is a specialized educational advisor. She lives in Switzerland with her husband and their two daughters, Ornella (27) and Mélie (24.5) who was diagnosed with PPP2R5D at the age of 22. Laure connected with the Jordan's Syndrome community to share experiences with other parents and try to find answers to questions she had been asking for many years about her daughter's neurodevelopmental disorders.
When she heard about the Ambassador program for Jordan's Guardian Angels, Laure wanted to help and support francophone families to help break the barriers from being isolated when caring for a loved one with a disability. She is happy to support francophone families to allow them to ask questions and find the information they are looking for about their children's development, which can be very difficult when you do not master a foreign language.

Laure Galvani est conseillère pédagogique spécialisée. Elle vit en Suisse avec son mari et leurs deux filles : Ornella (27) et Mélie (24,5) qui a reçu son diagnostique de PPP2R5D à 22 ans. Laure s'est connectée avec la communauté du Syndrome de Jordan pour partager des expérience avec d'autres parents et tenter de trouver des réponses à des questions qu'elle se posait depuis de nombreuses années sur les troubles neurodéveloppementaux de sa fille.
Lorsqu'elle a entendu que Jordan Guardian's Angels a annoncé vouloir constituer un groupe international de parents ambassadeurs, Laure a voulu apporter de l'aide aux parents francophones et les soutenir, car il est important pour elle de ne pas s'isoler quand on prend soin d'une personne avec des besoins spécifiques. Elle se réjouit de soutenir les familles francophones, de leur permettre de poser des questions et de trouver les informations qu'elles recherchent sur le développement de leurs enfants, ce qui est très difficile quand vous ne maîtrisez pas une langue étrangère.

Liane Doll

Mom
German Speaking Regions
German

Liane Doll is a technical draftswoman, currently working part-time in her husband Florian's company in the office and organizes everything around the house and the three children, Rafael (8), Elia (5) and Nicolas (almost 3) . The family lives in southern Germany in Oberkirch in the beautiful Black Forest area. Nicolas received his PPP2R5D diagnosis at the age of 15 months. Through Jordan's Guardian Angels, the family found a lot of support from other families around the world. The exchange with other German speaking families is especially helpful, because first of all it is easier to speak in the mother language than in a foreign language and secondly the health systems, therapies and possibilities are very different in every country. Since the beginning of 2021, Liane has organized regular Zoom meetings for German-speaking families to discuss current topics or share information. She has also set up a WhatsApp group for a quick exchange. Therefore, she is the perfect parent to join the Ambassador Program and continue to bring all German-speaking families together to support new families with the many questions especially directly after receiving the diagnosis.

Liane Doll ist Technische Zeichnerin, aktuell arbeitet sie in Teilzeit im Unternehmen ihres Mannes Florian im Büro und organisiert alles rund um das Haus und die drei Kinder, Rafael (8), Elia (5) und Nicolas (fast 3) . Die Familie lebt in Süddeutschland in Oberkirch im schönen Schwarzwaldgebiet. Nicolas erhielt seine PPP2R5D-Diagnose im Alter von 15 Monaten. Durch Jordans Guardian Angels fand die Familie viel Unterstützung von anderen Familien weltweit. Vor allem der Austausch mit anderen deutschsprachigen Familien ist sehr hilfreich, weil man sich erstens in der Muttersprache doch leichter tut als in einer Fremdsprache und es zweitens in jedem Land unterschiedliche Gesundheitssysteme, Therapien und Möglichkeiten gibt. Seit Anfang 2021 organisiert sie regelmäßige Zoom-Meetings der deutschsprachigen Familien um aktuelle Themen zu besprechen oder Informationen zu teilen. Auch eine WhatsApp-Gruppe für einen schnellen Austausch hat sie eingerichtet. Daher war es für sie selbstverständlich, dem Ambassador Programm beizutreten und weiterhin alle deutschsprachigen Familien zusammenzubringen und neue Familien bei den vielen Fragen gerade direkt nach der Diagnose zu unterstützen.

Emma Crofskey

Mom
Australia & New Zealand
English

Kia ora, my name is Emma and my partner is Joe. We live in the coastal town of New Plymouth, New Zealand with our two beautiful children George (10) and Lucy (7). George was first diagnosed with Jordan's Syndrome when he was 3 years old and I still remember my first video chat with Nancy on the other side of the world! At that stage we were the only two families that we knew of with children who had PPP2R5D and that connection meant so much to me. The fact that I could talk to someone else embarking on the same journey and share and swap stories on our kids made me feel like I wasn't doing this on my own. That's why I think it is hugely important that there is the opportunity to connect with parents, caregivers and families who have family members with a Jordan's Syndrome diagnosis, to share the information I have and to offer advice and support along our journey.

Keren Avni

Mom
Israel
Hebrew

We are Keren and Gali Avni, the parents of Omri (11 years old) and Michal (8 years old) and we live in Haifa, Israel. Michal was born in March 2015 and was diagnosed with Jordan's Syndrome when she was 15 months old. We joined the clinical research on the syndrome from the moment it started, and we support the activities of JGA that accompanies the families and the research.
A little about us: Keren is a PR manager and loves pilates and yoga, and Gali is a UX person and enjoys drawing, snowboarding and surfing. We really like walking and hiking in nature and often do it as a family.
Since Michal was diagnosed with the syndrome, we have been active in the world of special needs and rare diseases. Among other things, we established a Facebook group called "בהתאמה אישית", whose purpose is to be a platform for discussions and consultations regarding accessibility and various supports that children and adults need and that are not always available to everyone. We also give lectures, work to raise awareness through the media, are active in groups of parents of children with special needs, and more.
There are a few families in Israel who are dealing with Jordan's Syndrome, so it is important for us to create a network of support and help and serve as a home for every new families that receives a diagnosis of Jordan's Syndrome. We also have the support and knowledge from the international community of families and that's a lot without a doubt. We invite any new family from Israel or speaking Hebrew - to contact us, we are here for you and for us 😊.

אנחנו קרן וגלי אבני, ההורים של עמרי (בן 11) ומיכל (בת 8) ואנחנו גרים בחיפה, ישראל. מיכל נולדה במרץ 2015 ואובחנה עם תסמונת ג'ורדן כשהייתה בת שנה ו- 3 חודשים. הצטרפנו למחקר הקליני אודות התסמונת מרגע שהוא יצא לדרך ואנחנו תומכים בפעילות ארגון JGA המלווה את המשפחות ואת המחקר.
קצת עלינו: קרן היא מנהלת יחסי ציבור וחובבת פילאטיס ויוגה וגלי ונהנה לצייר, לגלוש בסנובורד ולגלוש בים. אנחנו מאוד UX הוא איש אוהבים לטייל בטבע ומרבים לעשות זאת כמשפחה.
מאז שמיכל אובחנה עם התסמונת, אנחנו פעילים בעולם הצרכים המיוחדים והמחלות הנדירות. בין היתר, הקמנו קבוצת פייסבוק שנקראת "בהתאמה אישית", שמטרתה להוות פלטפורמה לדיונים והתייעצויות בנושא הנגשות ותמיכות שונות שילדים ומבוגרים זקוקים להם ולא תמיד זמינים לכולם. אנחנו גם מעבירים הרצאות, פועלים להעלאת מודעות באמצעי התקשורת, פעילים בקבוצות של הורים לילדים עם צרכים מיוחדים ועוד.
בישראל יש משפחות בודדות שמתמודדות עם תסמונת ג'ורדן, ולכן חשוב לנו לייצר רשת תמיכה ועזרה ולשמש בית לכל משפחה חדשה שתקבל אבחון של תסמונת ג'ורדן. יש לנו גם את החיבוק, התמיכה והידע שאנחנו מקבלים מהקהילה הבינלאומית של המשפחות וזה המון ללא ספק. אנחנו מזמינים כל משפחה חדשה מישראל או דוברת עברית – ליצור איתנו קשר, אנחנו פה בשבילכם ובשבילנו 😊.