

TRANSITIONS KIDS TIMES

Meeting Families as They Are, Where They Are

This month Transitions Kids recognizes worldwide rare disease month. Please see [National Organization of Rare Diseases \(NORD\)](#) NORD “advances practical, meaningful, and enduring change so people with rare diseases can live their fullest and best lives. Every day, we elevate care, advance research, and drive policy in a purposeful and holistic manner to lift up the rare disease community.”

Integrative and Holistic

How to Illuminate a Building for Rare Diseases Day

Welcome Allyson Mattingly!

Choosing TK for my BSW internship was not a difficult decision. I shadowed Mariah a year ago and was able to experience the good that TK does for the community and how well everyone here works as a team. As for myself, I take on a lot of different roles at my university, NC State. I am president of the Baccalaureate Student Social Work Association and work as a resident advisor. A fun fact about myself is that I have played clarinet for 11 years!

Creative and Innovative

TK Parent Facebook Group

Looking for a way to connect with other TK parents and families? We have created a private Facebook group that invites families to connect with each other, support each other, and build a community. Please feel free to use this group in ways that feel supportive to you and your family! To become a member of this group, please use this [link](#) to submit your email address that is connected to your Facebook account. An invitation to join the group will be sent to your email.

Follow TK on Social Media

[TK Facebook - Transitions Kids](#)

[TK Facebook Group - Parents and the Safe Space](#)

[TK Instagram - transitionskids](#)

[TK Tik Tok - transitionskidsnc](#)

Accountability and Advancement

Join us for a **Patient & Family Advisory Committee (PFAC)** virtual meeting.

What is PFAC? PFAC is a space for those who have worked with TK to collaborate with the organization to improve and develop practices and policies that are informed by patient/family perspectives. The goal of PFAC is to support TK in improving and evaluating their practices and policies by patient engagement, collaboration, and creative innovation. PFAC quarterly meetings are held virtually via Microsoft Teams Video and facilitated by Transitions Kids team members.

When: Tuesday, April 16

Time: 5:30–7:00 pm.

Register [HERE](#)

If you have any questions about PFAC, please contact Abby Yuan ayuan@transitionslifecare.org or Siena Buckley sbuckley@transitionslifecare.org.

Engagement and Collaboration

Bereavement Groups

KidsZone

She Shed

Grief Academy

Please see our [Events Calendar](#) for registration and details.

Wonder and Whimsy

What is Rare Disease Day? (video)

HOW YOU CAN GET INVOLVED WITH RARE DISEASE DAY

Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. Since its creation in 2008, Rare Disease Day has played a critical part in building an international rare disease community that is multi-disease, global, and diverse—but united in purpose.

Join the [Global Chain of Lights](#) this Rare Disease Day. Together we will light up our monuments, our public spaces, our buildings, homes, hospitals and more. These lights show our resilience and strength towards a brighter future. Collectively, we can improve the lives of the **300 million people worldwide** living with a rare disease.

SCREEN THE VIDEO



Stream to your TV or laptop, fill your home with colour, **29 February, 7pm**. Share your story online with the hashtag **#LightUpforRare**

GET CREATIVE



You could create your own **window display** - with coloured lights, painted pictures, tissue paper collages or your drawings - however you like to get creative, share your colours!

WANT TO DO MORE?

Start a conversation with the people in your community to help spread awareness of people living with a rare disease. **Share your story**, or share the story of people who inspire you. The more voices that join us, the louder we can be in our demand for equity.

Check out all the **events and activities** happening around the world. Here you can find and join patient organisations, and **join your community**. You can even create your own event and post it to the website, to raise awareness or raise donations.

Download a whole host of **campaign materials** - from social media graphics, videos, posters, badges, banners and toolkits. We've got everything you need to help raise awareness, **your way**.



#LightUpforRare this **#RareDiseaseDay**

[TK Facebook - Transitions Kids](#) [TK Instagram - transitionskids](#) [TK Tik Tok - transitionskidsnc](#)