

CELEBRATING THE 4TH OF JULY

The 4th of July can be a time of joy, togetherness, and tradition but when you're parenting a child with Hunter syndrome, celebrating safely and inclusively takes a little extra planning. At Project Alive, we know that every family has different needs, and no two celebrations look the same. Whether you're staying home or joining a family gathering, here are some ideas and considerations to help you make the most of Independence Day.

PLAN FOR SENSORY SENSITIVITIES

Fireworks, loud music, and large crowds can be overwhelming for many children, especially those with sensory processing difficulties. Some tips:

- Opt for daytime activities like a picnic, backyard games, or a small neighborhood parade.
- Consider noise-canceling headphones if you'll be near fireworks or loud events.
- Watch fireworks on TV or from a distance (inside the car or home) to enjoy the visuals without the noise.

CREATE INCLUSIVE TRADITIONS

Simple traditions can have a big impact. Try:

- Decorating the house together with red, white, and blue paper crafts.
- Making themed snacks that are safe and easy to eat for your child.
- Reading or watching age-appropriate stories about why we celebrate the holiday.

These activities allow your child with Hunter syndrome and their siblings to feel included and engaged, no matter their ability level.

SIBLING INVOLVEMENT

Siblings often carry a lot of emotional weight and responsibility in rare disease families. Use the holiday as a chance to connect:

- Let siblings help lead an activity or craft.
- Give them space to join friends or cousins for fireworks or a later event if the rest of the family stays home.
- Acknowledge their flexibility and support with a small surprise or thank-you.

www.projectalive.org



PROJECT ALIVE

CELEBRATING THE 4TH OF JULY

At Project Alive, we see the beauty in every version of family life. Holidays like the 4th of July are a reminder not just of independence, but of community, the people who love and show up for each other in big and small ways. We hope your family feels connected, included, and supported this July 4th. If you'd like to share how your family celebrates the holiday, email us at sarah.napier@projectalive.org or tag us on social media using #ProjectAlive4th.

TALK WITH EXTENDED FAMILY AHEAD OF TIME

If you're gathering with extended family, a quick conversation beforehand can make all the difference:

- Let them know what your child needs (e.g., rest periods, special seating, adapted food).
- Encourage relatives to include your child in conversations, even if communication is limited.
- Share ideas for meaningful interaction, like singing songs, blowing bubbles, or looking at a picture book together.



STAY FLEXIBLE AND GRACE-FILLED

Plans may change. Your child may tire quickly or become overstimulated. That's okay. Celebrating doesn't have to be perfect, it just needs to be yours.

SAFETY FIRST

If your child is medically fragile or prone to wandering:

- Make sure identification is worn.
- Bring medications and feeding supplies in a portable cooler.
- Stay hydrated and keep shaded options available if outside.

CAPTURE THE MOMENTS

Even if you're celebrating at home in pajamas watching a cartoon parade, that's still your version of the 4th. Take photos, record short videos, or write a few sentences about what made the day special. These become treasures.



www.projectalive.org



PROJECT ALIVE