PROJECT ALIVE

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Date

The Honorable Congressperson, Senator Name
Office Address
City, State, Zip

Dear Congressperson/Senator Name,

I am writing to you as a [parent/guardian/family member] of a child living with Hunter syndrome (Mucopolysaccharidosis II, MPS II), a rare and progressive genetic disorder that primarily affects boys. Without treatment, children with Hunter syndrome face a life expectancy of just 10-20 years. As a family, we are deeply concerned about the lack of accessible treatments for this devastating disease, and I am reaching out to urge your support on key policy issues that could save my child's life and others affected by rare diseases.

1. Support the Accelerating Kids Access to Care Act

Children with rare diseases like Hunter syndrome often face barriers in accessing critical clinical trials. The **Accelerating Kids Access to Care Act** will help expedite access to clinical trials, ensuring that children like mine have the opportunity to participate in potentially life-saving research. I ask that you support this legislation to remove obstacles that stand between children and the treatments they need.

2. Support the Rare Pediatric Disease Priority Review Voucher Program

I also urge you to support the **Rare Pediatric Disease Priority Review Voucher Program**, which incentivizes the development of treatments for pediatric rare diseases. This program has been essential in bringing therapies to market faster for children with rare diseases and could be the key to accelerating treatment options for Hunter syndrome.

3. Ensure Federal Biomedical Research Funding and Public Health Agency Support

It is critical that federal funding for biomedical research, especially through the **FDA** and **NIH**, be maintained and prioritized. Without proper funding and leadership at these agencies, life-saving treatments for progressive, terminal diseases like Hunter syndrome will not be able to progress through clinical trials or reach our children. Federal support is essential to ensuring that treatments are developed and made available to children who need them most.

I hope you will stand with families like mine in supporting these important pieces of legislation that will bring us one step closer to treatments that could save our children's lives. Thank you for your time and attention to this urgent issue. I look forward to your support and action on behalf of children with Hunter syndrome and other rare diseases.

Sincerely,

Your Name

Your Address

Your Email/Phone Number