



### July 2022 Newsletter

Just two short months ago, we made the cross-country move from Arizona to North Carolina. Leaving behind a home that held so many memories was hard, but we are happy to be closer to family. We are settling into our new home, enjoying a new school, and exploring all that Chapel Hill has to offer.

While this move has brought positive change, it hasn't altered the relentless toll that juvenile Batten is taking on our girls. Amelia's communication struggles continue and frustration can turn to outbursts of anger. Recently, Makenzie went on a hunger strike landing her in the hospital with dehydration. Sleepless nights, a common Batten symptom, are impacting the entire family.

Despite it all, we still find happy moments each day. And we can't thank you enough for following along on this journey.



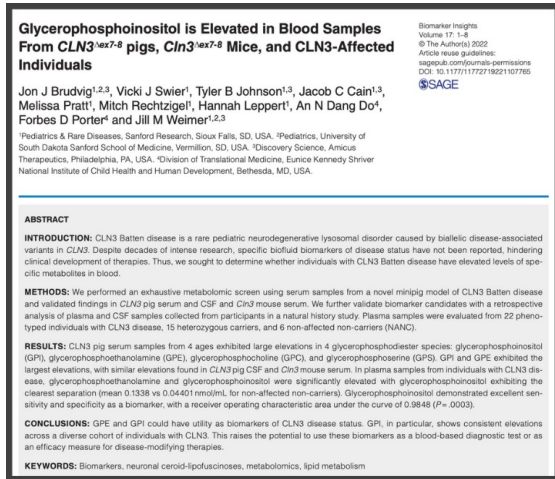
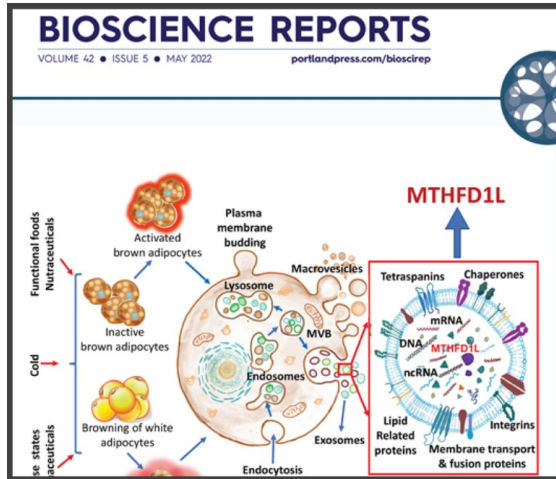
A handwritten signature in black ink, consisting of a stylized 'K' followed by a horizontal line. Below the signature, the word 'MOM' is written in a simple, sans-serif font.

A handwritten signature in black ink, consisting of a stylized 'D' followed by a horizontal line. Below the signature, the word 'DAD' is written in a simple, sans-serif font.

## Fore the Cure

### Published Research

We are excited to announce two ForeBatten funded research projects have recently been published! Both of these studies offer clues into the elusive function of the CLN3 protein. Click on images below to access studies and learn more.



## Fore the Journey

### Update: Fore The Journey Fund

So far this year, [Fore The Journey Fund](#) fund has provided a variety of awards from a porch extension for much needed shade, to an electric bike, and a special wheelchair designed for the beach.

Here is just one of the testimonials from a happy Batten mom:

*"Last summer I sat at the kitchen counter frustrated by the inability to use our back patio because of the intense heat. Ely loves being outside, but the amount of money to put a cover over our patio was out of our budget and his body couldn't take the direct sunlight for long. In July, we got our Batten family conference box and inside was a little info card about the Fore The Journey Fund. Their goal was to bring joy to families journeying through Batten disease. I felt a prompting in my heart to see if they would consider funding a covered patio so Ely could enjoy his outdoor space year around. Honestly, I thought the ask was too big. But they said YES!!! We had to wait until December for installation but this summer our patio has already been more accessible because of the covered space. And it has brought Ely so much joy! Thank you Fore The Journey and BDSRA."*

Our vision to provide joy to Batten families continues through the Fore The Journey fund.

### Beat the Heat/Beat Batten

For the second summer, we held Beat the Heat/Beat Batten events across the country. These fun events are a great way to support ForeBatten and spread awareness of juvenile Batten disease. If you would like to host an event, please send a note to Carol at [carol@forebatten.org](mailto:carol@forebatten.org). All you have to do is pick a date and place and invite your friends for some cool treats. We do the rest!





## ForeBatten

**Mark your calendars!** Our 5th annual Take A Swing Fore Batten online auction runs 9/27/10/11. If you have an item or experience you would like to donate, please contact Stan Kahn at [stan@forebatten.org](mailto:stan@forebatten.org) or 440.725.3395. Get a jump start on your bidding by visiting [ForeBatten2022.givesmart.com](http://ForeBatten2022.givesmart.com) to check out the growing list of auction items.

<p>009</p> <p>Dormie Network - 1 yr Membership</p>	<p>102</p> <p>Sand Hills Golf Club</p>	<p>192</p> <p>Clear Creek Tahoe</p>	<p>199</p> <p>Bluejack National Golf Course</p>
<p>124</p> <p>Old Town Club</p>	<p>127</p> <p>Liberty National Golf Club</p>	<p>261</p> <p>Baltusrol Golf Club</p>	<p>272</p> <p>Merion Golf Club</p>