

LET'S GO PROPIONIC ACIDEMIA!

WHAT'S UP WITH AIDEN???

Hemoshear Clinical Trial "HERO"

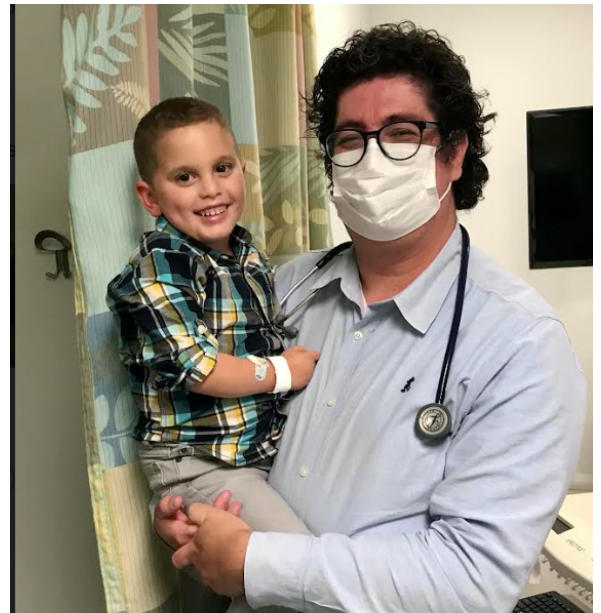
Lurie Children's Hospital

*Aiden is nearing completion of Phase A
of the clinical trial. (whoo hoo!!!)*



This first phase is focused on safety, but the kicker to be able to move to phase B, is that they need at least 12 participants enrolled, which they don't have yet. There are a total of 3 phases. I know it isn't feasible for all our kiddos to take part, but if you can, please check it out and consider enrolling. This will allow those who are currently enrolled to move forward to phase B and onto completion to see if the drug will prove as a beneficial treatment.

We live in Ohio and travel to Chicago once a month for visits. I can't say enough about Lurie Children's & the positive experiences we have had with Dr. Prada, Carolyn, and the whole research team. They are compassionate, fun, trustworthy and have a sincere desire to see optimal results from the study! If you have any questions, please email cserbinski@luriechildrens.org. I know Dr. Prada and Carolyn would be happy to discuss the details of the trial.



*We are thankful to God, Hemoshear, and to Lurie Children's Research team
for making this clinical trial possible.*

We hope & pray that the study will yield better treatment to all of those affected with PA.

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ABOUT AIDEN

Fun Facts

- 5 yo and has a twin sister, Ava
- loves his family
- primarily gtube fed
- loves taking his levocarnitine by mouth
- receives bolus feeds three times through out the day, 6 hours continuous feeds through the night.
- receives ST and OT weekly
- currently working on being potty trained!

Favorite activities & foods

- playing in the sand & mowing the lawn
- veggie straws with guacamole

Main struggle from P.A.

- constipation - giving 4 oz of prune juice/ day is helping tremendously

