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UNIVERSITY OF DELAWARE **CENTER FOR DISABILITIES STUDIES** 

### Introduction

AS A MOM OF A CHILD WITH A RARE GENETIC DISORDER I FEEL LIKE THERE IS NO ONE WHO WILL GIVE ME INFO TO MAKE GOOD EDUCATIONAL/MEDICAL CHOICES.

I HAVE FOUGHT TO UNDERSTAND MY SONS CONDITION FOR THE PAST SEVERAL YEARS, WHEN I THINK I MAY HAVE FOUND HELP IT FALLS APART.

I began my journey about 6 years ago with my son. It was a long fight with his neurologist to try and see if epilepsy is in fact the correct diagnosis. After several tests it was determined that my son has KIF1a.

Due to this he struggles in school. He is currently in the 11<sup>th</sup> grade but reads at a much lower level.

I have had nothing but problems with the school system. I have been told that the teachers will send home graded papers that I never receive, when I ask for certain accommodations on his IEP I get told that can't happen at this time.

My son is in ESY also and it has never taught or retaught him anything that will help him in the next school year.

My project is to show how the education system is failing our kids. ESY-helping to keep skills and if you see the photos it looks like this is for a child going into 1<sup>st</sup> grade not 12<sup>th</sup>.



# **LEND Leadership Project** Kelly Bankert University of Delaware LEND Program

## Methods

https://npen.org/

#### DELAWARE

• The mission of CHILD, Inc. [www.childinc.com] is to be the leading advocate for Delaware's children. They provide creative prevention and treatment programs that meet the changing needs of families and serve dependent, neglected and abused children and their parents. They also provide programs for those involved in domestic violence situations, especially children. By protecting the victims and treating those responsible for acts of domestic violence they help children heal.

What is NPEN?

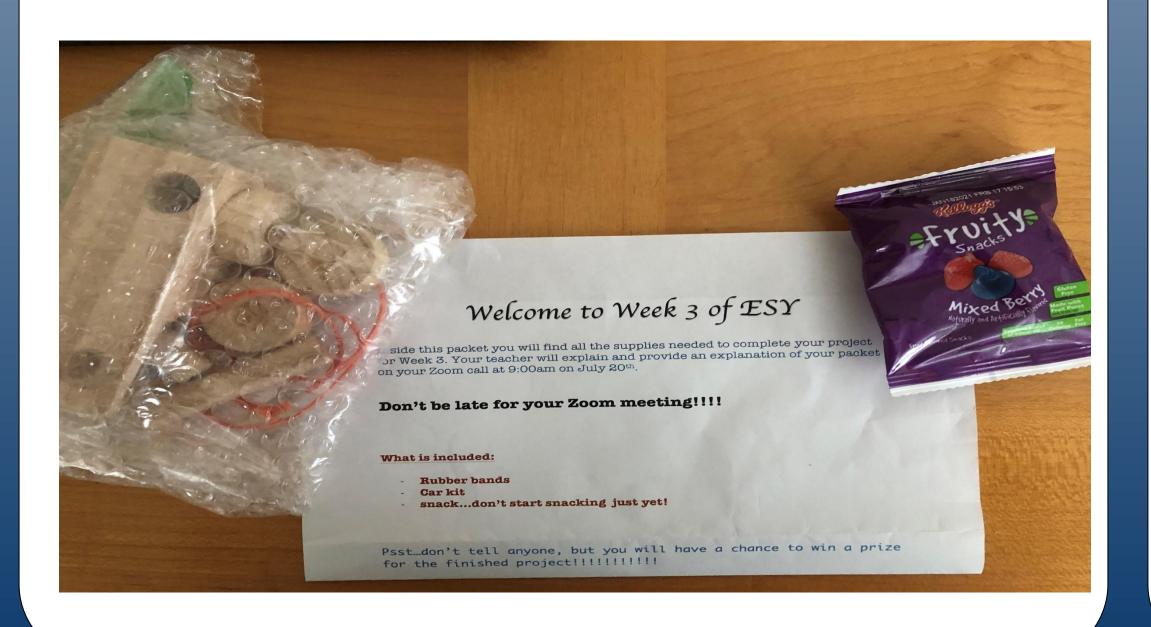
NPEN is a national organization that promotes the field of parenting education and encourages information sharing, professional development and networking opportunities for individuals who educate and support parents.

https://picofdel.org/our-work/ Parent Information Center

https://www.dhss.delaware.gov/ddds/ Shares info on Respite, self advocacy, etc.

http://www.familyshade.org/ Resources, events and organizations

There are so many groups that you can join and learn from. I have gone to a few meeting and groups. In the end none of these gave the feeling that they were for the child and family. It had always felt like to me that the info that is shared is all that there is. I have found that is not true.



## Results

- 2020 World Best Education Systems 1st Quarter Rankings 2020 First Quarter Rankings
- . Finland
- 2 Denmark
- 3. South Korea
- 4. Hong Kong
- 5. Norway
- 6. Slovenia
- 7. Israel
- 8. Sweden
- 9. United Kingdom
- 10. Poland
- 11. Singapore
- 12. Japan 13. Ireland
- 14. Taiwan
- 15. Kazakhstan
- 16. Estonia
- 17 Hungary
- 18 Russia
- 19. Belgium
- 20. United States

RANK	STATE	HIGHER	PRE-K-12
		a	
1	Massachusetts	27	1
-	Massachusetts	20	
2	New Jersey	30	2
3		1	27
	Florida		
4		2	19
	Washington		90357
5	1000	37	3
	New Hampshire		
6	Nebraska	7	9
7		14	8
	Virginia		
8		41	4
	Vermont		
9		8	13
	lowa		
10		6	22
			2000-0

Delaware is ranked 23rd

I would love to see help for all kids. After being a part of LEND I would like to move forward with a parent group. A group that will support ALL children and their families. The group will be for children who are just beginning the education thru adulthood. Allow families to talk to one anther and learn what accommodations and supports are out there for them. A group that can meet once a month to discuss issues within the education system.



### Conclusions

### Bibliography

<u>1</u>https://npen.org/ <u>2</u>https://picofdel.org/our-work/ <u>3 https://www.dhss.delaware.gov/ddds/</u> <u>4</u>http://www.familyshade.org/