

# PSA Honors Program

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*Children's Book: PANDAS*

Education, Elementary Teacher  
Applied Psychology: Human Services  
Psychology

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## **Artist's Statement**

### **Story Background:**

As a Psychology and Elementary Education major, I am interested in children's books and those specific to mental health. Writing and publishing a children's book has always been something that I wanted to do. I decided to choose a topic close to me, Obsessive Compulsive Disorder (OCD), particularly Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS). In 2006, my brother was showing signs of OCD behavior. After being seen by mental health professionals, he was diagnosed with PANDAS. This is not a condition widely accepted or known throughout the mental health and professional healthcare community. It is still very controversial and some health professionals do not accept the condition. That being said, in the past year there has been more attention brought to it in the media through talk shows and parenting magazines. My choosing this topic in particular stems from the fact that many individuals do not know about this condition and it is not easily explained to a child.

Originally, I wanted to write an informative book about OCD and PANDAS. I decided not to go down this route as I wanted the book to be for young children to learn about PANDAS who may have not experienced it. I wanted the child while reading the book, to experience empathy toward individuals facing this condition more than just understanding the condition itself. I did have my brother in mind before I wrote the story. He experienced various stages of grief the last six years. It is still difficult for him to understand why he is different. I remember him telling me a story of how he asked his friends if it bothered them to cut the tags off of their toys. He was in kindergarten at the time. When he told me about this, he appeared upset that his friends did not share

the same struggle and they didn't understand why it was so hard for him to cut the tags off. Thinking back to that story, I wanted to focus my audience on those not facing the condition. There are more resources for those facing the condition to help cope with it rather than the peers of children with OCD and PANDAS. I do believe that those with the condition would benefit from the book as well.

As I thought about how to write about the story, I had my brother in mind (who was 8 at the time). Thinking of a boy who doesn't like to read, I wanted the story to be adventurous. Consequently, the adventure into Capernia and the PANDAS dragon was developed. Originally the book would have been written similar to *The Magic School Bus* books as I wanted Dave to discover what it was like in Charlie's mind. I wanted my story to be unique so I made it an adventure rather than a biology, specifically the brain, lesson. As the story developed, my focus on the story did as well. Instead of the story being more educational, it became a story more about friendship and overcoming struggle. For my target audience, I feel that this was appropriate.

I also debated on if I would have Charlie overcome the OCD symptoms. Originally, I wanted a story where Charlie would work with a therapist using cognitive-behavioral therapy to overcome the effects. This was however personally-charged. My parents did not bring my brother to therapy for his condition despite my encouragement. After analyzing my own motivation, I realized that I should not put this in my story as it may distress my family members a great deal. Instead I decided to keep the idea of cognitive-behavior therapy in the book. I wrote it in a very simple fashion and I had Dave "stop" the thought through self talk as it was coming to him in the book. I wrote it very simply. A child would most likely need to say more than "no" to stop the

thought process. I decided not to make the story more elaborate by adding this as it might confuse the audience more.

### **Illustrations:**

For the illustrations, I decided to do collage illustrations made out of material. Having a fair to poor background in art, I choose to do illustrations that I was comfortable with. I choose to do a collage style. In one of my classes at Bemidji State University for Elementary Education, I needed to do a collage using fabric pieces. When I saw how well it copied, I decided to use this for my illustrations. I started collecting pieces of fabric and bought some colors that I knew I would need for different areas. I first made a thumbnail sketch of each page to coincide with the story. I then drew larger pictures on large sheets of paper. I copied each page. I used one of the copies and I cut the shapes of the drawing out. I then used this as a stencil to cut each piece of fabric out. I then glued these onto another large sheet of paper. The only parts of the illustrations that are not done by fabric are the clouds and some of the faces. The clouds are made out of cotton balls and the faces were drawn on by a fine tip marker.

### **Research:**

Before I started the story, I need to do research on several aspects of my book. I researched Obsessive Compulsive Disorder and specifically how it affects children (under 12). I also researched PANDAS and how it is treated. Before I started, my knowledge of PANDAS was basic. I knew that it was brought on by Strep Throat and I knew that after it started to affect the brain, children affected by it showed signs of Obsessive Compulsive Disorder and tics. My knowledge in the treatment for PANDAS

was limited. I also did research on books written about PANDAS specific to my target audience, which is children under ten.

There are a couple known ways to treat PANDAS. I researched the most well known ones. The most popular ones I found were medical treatments. Medically, it is primarily treated with antibiotics. It also is treated by Steroids, IVIG (Intravenous Immunoglobulin) and Plasmaphoresis. I chose not use a medical treatment in my story as I wanted to stick with a behavior therapy that is closer to my field. The most common behavior therapies used to target PANDAS symptoms (typically used after a child has been treated for strep or medically treated first) are cognitive behavior therapy and exposure and response prevention I chose cognitive-behavior therapy as it is a more “self-help” approach and has shown to work well with adolescents and children.

When I researched children’s books related to PANDAS, I came up empty handed. I found more books for adults, but none related to PANDAS specifically. I did find some for children with OCD. One was written about a boy who uses cognitive-behavior therapy and medication to treat the OCD behaviors. It was called, *Mr. Worry: A story about OCD*. Another was called, *What to do when your brain gets stuck: a kid’s guide to overcoming OCD*. This book is more of a self-help work book. There were a couple of others that I looked at, but these two were the ones that I looked at the most in comparison to my story. *Mr. Worry: A story about OCD* is closer to my story with the storyline and focus. Before I read the book, I wanted to write my story very similar to how it was written. After reading it, I realized that it would be too similar and I wanted the audience to have a different perspective.

**Process:**

After researching PANDAS, OCD and treatment, I began outlining my story. At first my story started out to be educational. After writing several ideas down for the story, I had the idea that Dave would go into Charlie's head. I didn't want the story to be boring and I wanted children, in particular boys, to be drawn to it through an adventure. I also wanted to give the disorder an identity. I then came up with the PANDAS dragon. I wanted Dave to experience what it was like to be Charlie. For a child, I know this is a difficult concept to grasp and that they might not even grasp it even with an identity. That is when I decided that even if a child didn't understand that the PANDAS dragon was not really a dragon that lived in Charlie's brain, they would understand that Charlie was dealing with something very challenging for a child. I at first wrote the story where Dave kills the PANDAS, as in some cases after PANDAS is treated, the symptoms have drastically decreased.

I didn't however want a child to believe that another child could rid PANDAS just by overcoming it one time. Some children do face the challenges of OCD every day. I wanted Dave to realize this. Gillis was created as a character to help Dave understand what was happening to Dave. In some of the very early drafts, Dave was brought to the Queen of Capernia. The Queen then told Dave about how PANDAS could come back. I was advised that this was unnecessary and that it might confuse the reader to add another element to the already complex story. I then had Gillis tell this part of the story. At the end of the story, I was at first going to have Dave explain and talk to Charlie about the disorder. Again, I felt this would complicate the story more. I wanted the reader to really understand the concept that even though his friend was different, he needed to be a good friend to him. I felt that putting a note to parents would encourage the conversation of PANDAS between parent and child.

My hope is to have a parent explain the intricate parts of the story and PANDAS to the child. I also hope that the conversation of how important it is to be a friend to another classmate or peer who is struggling.

**Future:**

I hope to print this book in the future. I am not satisfied with the illustrations but I would like to publish the story if I could find an illustrator. If I cannot publish it through a company, I would like to self-publish my book online through createspace.com. This company is an Amazon company that works with writers to publish online e-books and on-demand books. The book would be offered online on the Amazon.com store and also as an e-book for Kindle. It also could be offered through an expanded distribution in which it would be available to academic institutions, libraries, bookstores and online stores. I also will continue to research PANDAS and follow the research done on it as it is becoming more known to the public.

I was informed recently that researchers identified a subset of PANDAS, known as Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS). This condition is very similar to PANDAS with the exception of strep throat being the cause. In PANS, OCD symptoms are triggered from an infection other than strep throat. Since this was first defined in 2010, little is known about this subset. I would like to continue to follow the research done on both PANDAS and PANS and in particular, the treatment. Since both the conditions themselves and the treatment are controversial, it will be interesting to see where the research goes.

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Hi, I'm Dave and my best friend is Charlie. Charlie and I have lots of fun together. We go sledding. We make forts and we play catch. Charlie and I have always been friends, but it wasn't always easy for Charlie and me.

When Charlie and I were six years old, Charlie got sick. After he got better, Charlie started doing things he didn't do before. Every time we went sledding, Charlie counted his steps up the hill.

"One, two, three...twenty four, twenty five..." This took a very long time.

I threw a snowball at him one time and he started counting over at one.

When we made forts, Charlie had to put the snow in a special spot or he would have to start again.

When we played catch, Charlie had to throw it a certain way, or he would have to do it again. Pretty soon, Charlie spent more time doing everything over and over and less time playing with me.

"Stop doing that!" I would tell Charlie, but then he would start to cry or scrunch his face up.

One day I asked Charlie why he did those things.

"It's because of the OCD", he said quietly and looked at the ground. I didn't know what OCD was and I didn't want to make my best friend sad.

..STOP  
going there..

..ONE, TWO THREE..



That night, I started to fall fast asleep thinking about the OCD...

“Who are you?” I heard someone ask.

I opened my eyes and looked around. There in front of me was a small creature.

“Who are you?” I screamed.

Suddenly I realized that I wasn't in my bedroom. I was outside somewhere, somewhere I had never been before.

“I am Gillis. I need to clear out the village. The PANDAS will be here soon”, Gillis said.

“The PANDAS? Who is that?” I asked.

“Don't look at me like you don't know about the PANDAS!” he scolded. Then he bent in close to my ear and whispered, “I shouldn't talk so loud. The PANDAS might be listening. Come with me. I will tell you all about it.”



Willis brought me to a cave-like opening.

“Don’t be scared, you’re safe in here,” he smiled.

“The PANDAS is a large villainous creature that wants to take over our wonderful village, Capernia.”

“Why don’t you just tell the PANDAS to leave?” I asked.

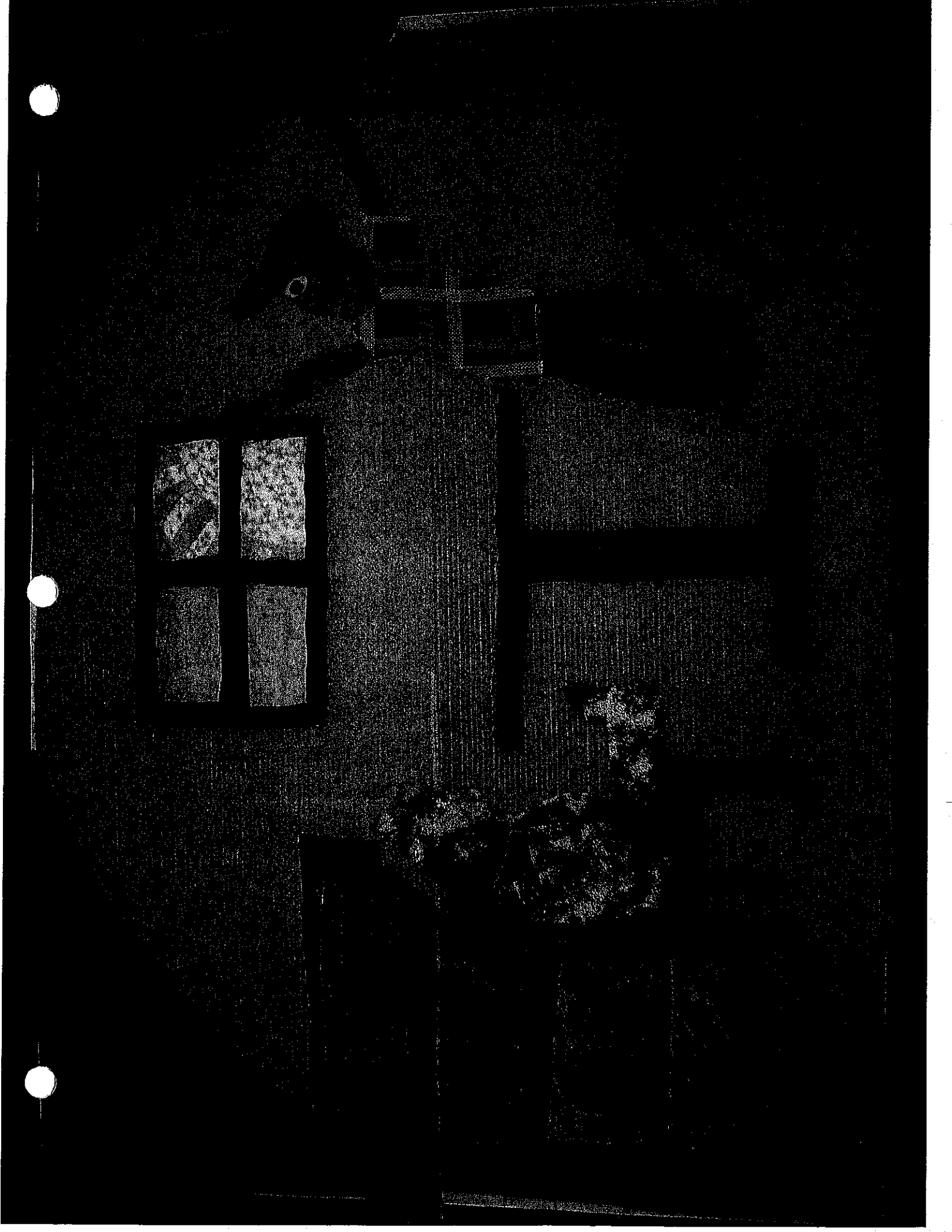
The little creature stared at me with a tear in his eye and said, “We can’t.”

“Why don’t you just battle the PANDAS then?” I asked.

Willis put his hands on his hips and said, “You can never beat the PANDAS. Many have tried, but he can’t be stopped.”

I looked down at the ground and then I had an idea.

“I will stop the PANDAS. I have a good arm and a good aim. My friend Charlie says so,” I said. The creature looked at me and smiled. “You can try.”



Suddenly I started to hear something calling “You need to count your steps before you leave....something might happen if you don’t....”

The little creature seemed to hear this because I heard him counting under his breath...one, two, three....

It reminded me of when Charlie counted.

“What are you doing?” I asked. The creature looked surprised that I saw him. “Nothing” he snapped, “The PANDAS makes us all do strange things.”

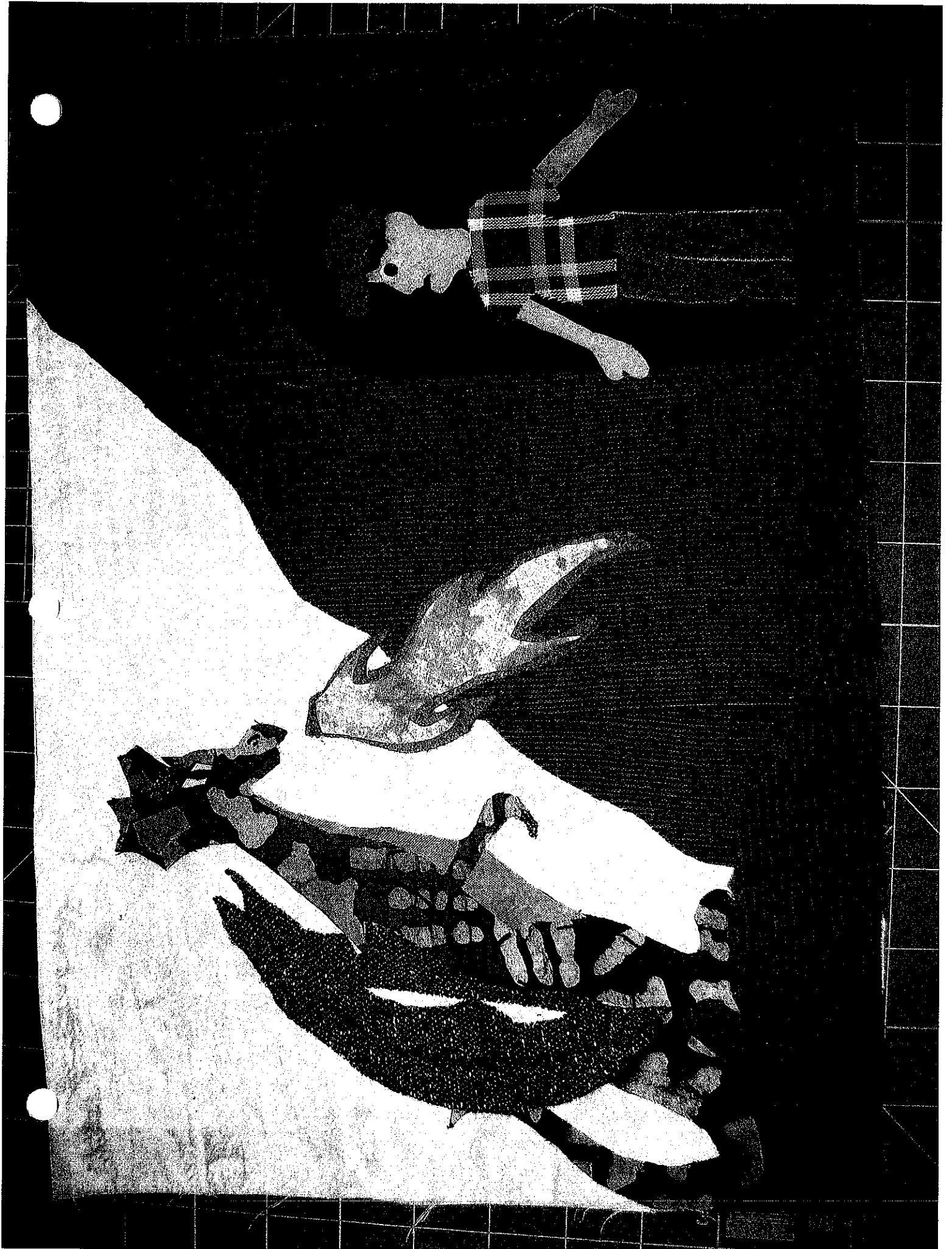
I started to laugh. “What could panda bears make you do?”

I started to leave the cave, but something startled me.

There in front of me was a large fire breathing dragon beast.

“The PANDAS!!” I heard Gillis shriek.

The PANDAS was not *panda bears*, but a real live dragon!!!





I started to step back and then the dragon yelled "Count your steps or something bad might happen." I scrunched my face. I wanted to cry. The dragon said it again, "Count or something bad might happen!!"

My stomach started to hurt so I started to count, " ...one two three....", as I continued to count, I saw the dragon slowly grow bigger and bigger. I kept counting until I stopped walking.

When I tried to walk again, the dragon screamed, "Count, count, or something bad might happen!!"

I didn't want to keep counting, but something made me do it. I could feel the dragon's power take over me. The bigger he grew, the harder it was for me to stop. Soon I started to hear other village creatures around me counting "10, 11, 12".

Count.

Count, or

some -

thing

bad

might

happen



We both started counting, and counting, and counting and counting.

I was getting tired and upset that the PANDAS was making me and all the other creatures in Capernia count too.



Counting helped my stomach feel better, but it also made me feel sad. Finally, I screamed “No, I will not count anymore!!”

The PANDAS turned at me with a glare in his eyes and squealed, “Noooooo!!” The great dragon then grew smaller. All the creatures stopped counting when they saw this. The PANDAS shrunk again.

“PANDAS, you have no right to tell everyone what to do!!” I yelled.

The PANDAS grew smaller.

“We will not count for you anymore.”

The PANDAS grew smaller still.

One of the Capernian creatures screamed out, “PANDAS go away!”

The PANDAS grew smaller and smaller as the creatures told it to go away.

Pretty soon the PANDAS was as small as a lizard and he scurried away.

Everyone cheered, “You did it, and you made the PANDAS leave. I started jumping up and down. “Yippee!”



"I am just glad that you won't have to see him anymore." I smiled.

Gillis replied, "I wish that was true. There is no way to get rid of the PANDAS. It will come back again." Gillis asked, "Dave, do you know where you are?"

"I am in Capernia," I said. "Yes, this is Capernia. Capernia is a place in your friend Charlie's mind."

"Charlie?" He nodded. "I am in Charlie's mind right now?" I asked

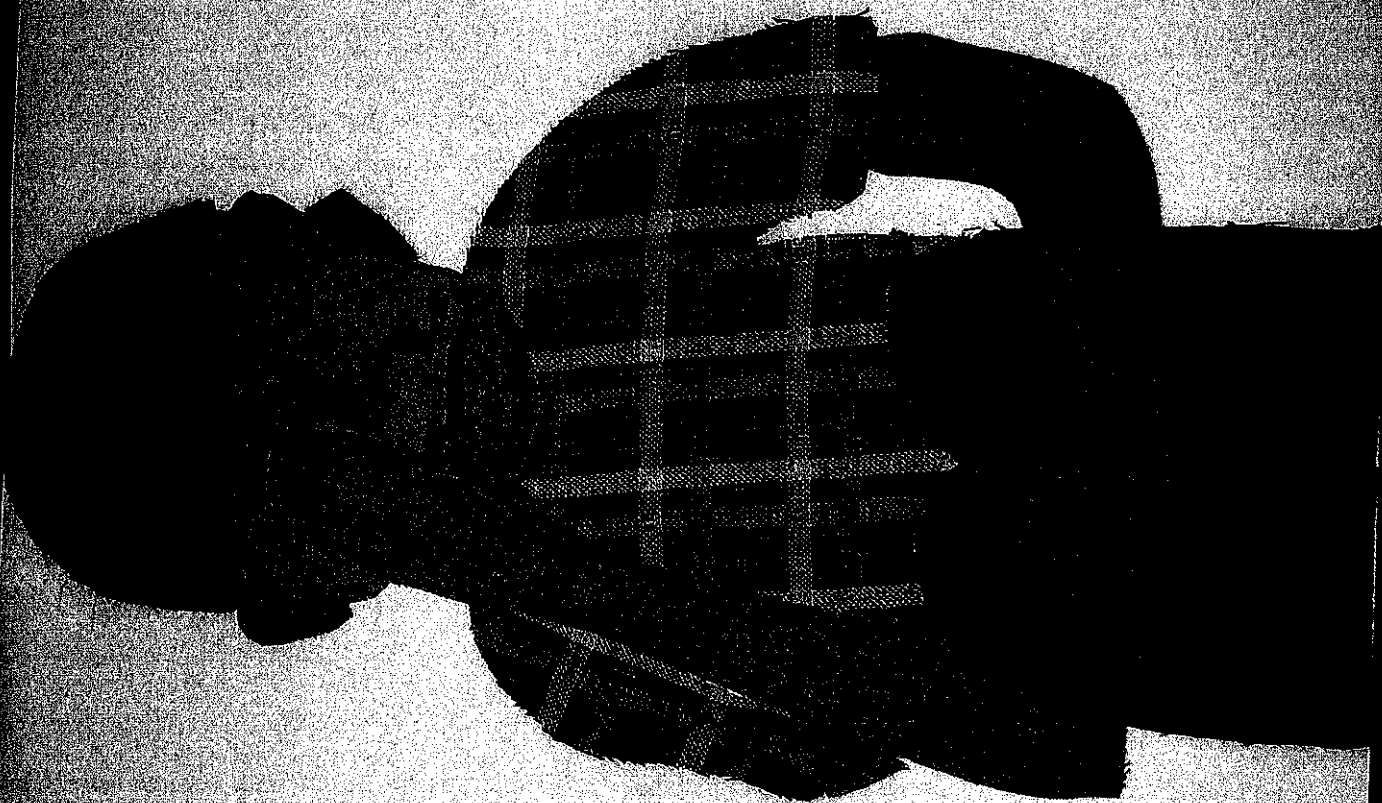
"Something like that yes."

"Why can't we destroy the PANDAS then?"

Gillis replied "The PANDAS creates thoughts that are untrue and tells them to Charlie. He does this many times a day. Sometimes he tells him to count and something it is something else. The PANDAS was born when Charlie got sick. It created OCD."

I then remembered that Charlie told me that he counted because of the OCD.

I started to cry. "If I get sick, will I get OCD or PANDAS?"





“No, probably not,” he said. “The PANDAS is only born in a couple of minds. And the OCD is only in some children’s minds. If there are one hundred children, only about one child has OCD and even less have PANDAS.”

“It’s still not fair. How come Charlie has to have it?” I asked

“It isn’t fair” he replied, “and it isn’t anyone’s fault. Not Charlie’s, not Charlie’s family, not you and not even his doctors. The best thing you can do is to be a good friend to Charlie, just like you were today to us.”

I stopped crying.

“Really?”

“Charlie has a lot going on in his mind. He has to fight the PANDAS several times a day. It’s very tiring and hard to do.” He said with a smile.

“I know” I said. “It was hard for me to have enough courage to say no.”

“Charlie needs someone like you, a good friend that will be there all the time for him.”

I started to smile.

“I can do that,” I said.

“I know”, Gillis smiled. “You can leave now. All you have to do walk to those trees over there” he pointed, “Don’t forget what I told you.”

“I won’t,” I said

When I started to walk toward the trees, a bright light shown in my eyes.



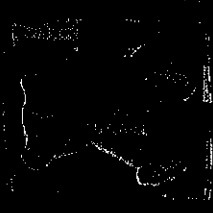
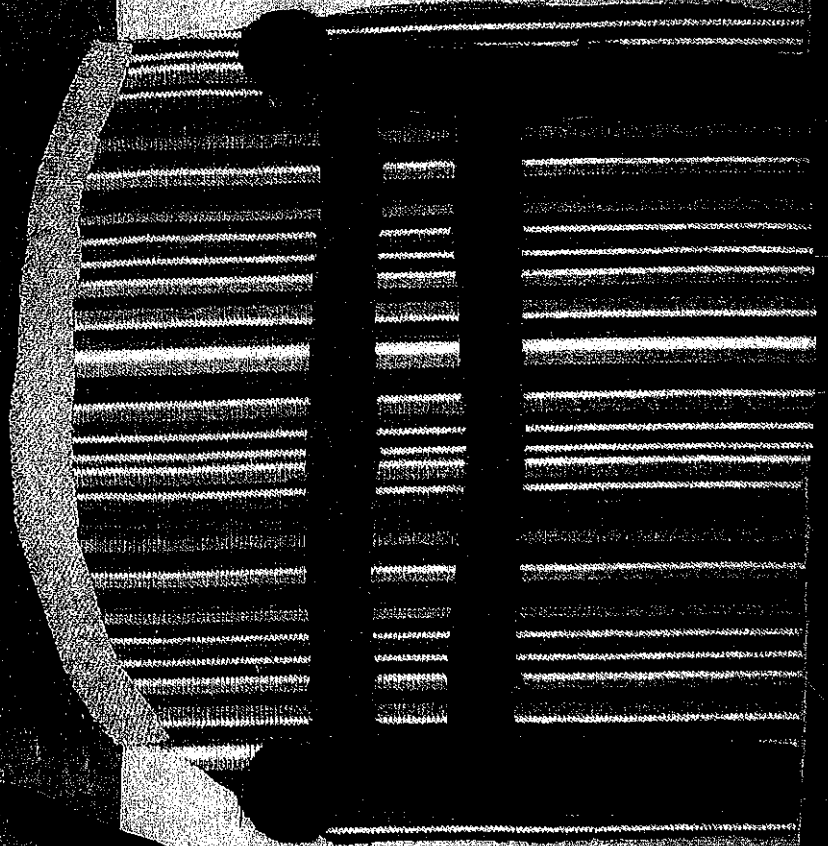
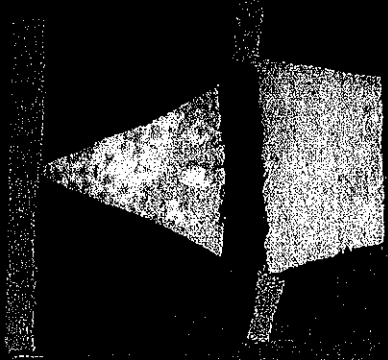
"Time to get up honey," I heard my mom say, "Time for school."

I looked around.

I was in my room.

I was home.

Yippee!!!!



When I got to school that day, I rushed to find Charlie.

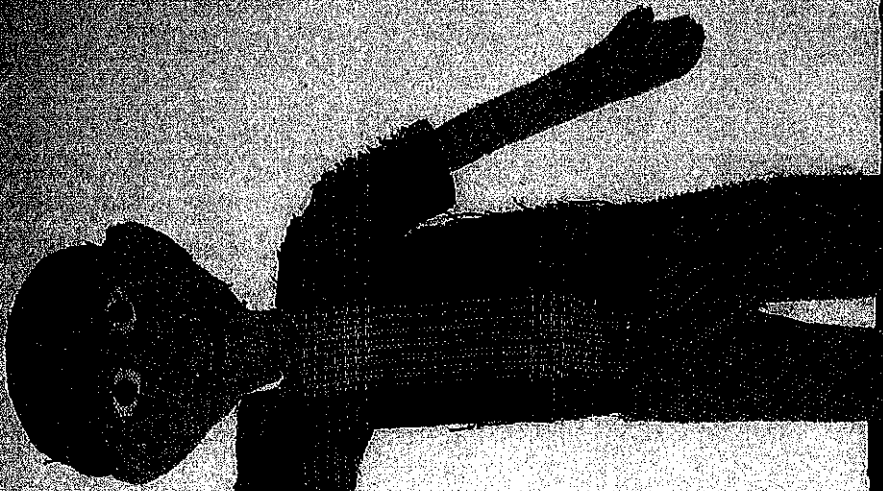
“Charlie, Charlie...you will never believe what happened to me!!”

I stopped. Charlie will probably think I am crazy if I tell him about my adventure...or dream.

“Charlie, you have a lot on your mind. I’m sorry I get mad sometimes at you. I am glad you are my friend and I always want to be your friend.” I said.

“Are you feeling okay?” he asked.

“Yes” I smiled. Charlie and I will always be friends. That night I dreamt that Charlie and I were in Capernia, fighting the PANDAS together.



### Note to Parents:

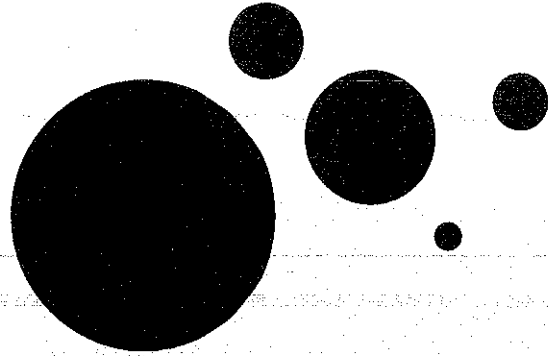
PANDAS, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections was first identified in 1998. It is considered a new and controversial disorder. PANDAS means that in some children, when exposed to Group A strep (strep throat), severe symptoms of Obsessive Compulsive Disorder (OCD) develop. Advocates of PANDAS believe that the bacterial infection of strep triggers the immune system to produce antibodies. In the case of PANDAS, instead of attacking the infection, the antibodies attack the basal ganglia. The basal ganglia is the part of the brain that controls emotions, behaviors and physical movements. This results in OCD behaviors and tics. It is believed that PANDAS affects only 10-30% of children with OCD and OCD only affects 1-2% of children. Treatment for PANDAS is still experimental and controversial. Some Doctors who treat PANDAS treat children by giving them antibiotics. Some treat children with a procedure called IVIG (intravenous immunoglobulin therapy) which is a blood cleaning procedure. This is an expensive procedure and can be overused. Other Psychologists treat OCD symptoms using medications or cognitive-behavior therapy, which is what this story is based on. It is unclear if PANDAS can be cured, but with all of these treatments and therapies, there has been improvement in the symptoms in some children. This book was created for children to empathize with children with PANDAS. It is also to show them that as a friend, the best thing they can do is to support them. For more information on PANDAS, please visit:

**<http://www.adhd.com.au/PANDAS.htm> and/or <http://pandasnetwork.org/>**



**HONORS THESIS:  
CHILDREN'S BOOK: PANDAS**

**Christina Timpe**



# IDEAS, IDEAS, IDEAS, IDEAS

- Initial Thesis
- Pythagorean Theorem
- New Ideas:
  - Children's book
  - PANDAS
  - Sexual Assault Policies in Universities
  - Teen Delinquency and Reading

# WHAT IS PANDAS?

- Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections. It was first identified in 1998 by Dr. Susan Swedo.
- In short, children diagnosed with PANDAS show symptoms of OCD or tics after having strep throat.
- The immune system attacks the brain instead of the infection.
- Antibiotics appear to decrease symptoms.

# PERSONAL STAKE

- o Brother diagnosed with PANDAS in 2006
- o First heard of PANDAS
- o Wanted the book more for children not diagnosed due to lack of understanding or empathy for condition.

# RESEARCH

- Needed to research, PANDAS, OCD and relative children's books
- Children's Books:
  - **Kissing Doorknobs:** T. Hesser
  - **What to do When Your Brain Get's Stuck: a Kids Guide to Overcoming OCD:** Dawn Huebner
  - **Talking back to OCD:** J March and C Benton
  - **Main Street: Keeping Secrets:** Ann Martin
  - **Mr. Worry: A Story about OCD:** H Niner
  - **Up and Down the Worry Hill:** Aureen Wagner

## OVERVIEW OF RESEARCH ON PANDAS

- The condition is brought on by strep throat (Type A streptococcus), attacking the basal ganglia
- Occurs in children 3 years old to about puberty
- Not enough evidence to support PANDAS in adults
- About 25% of children with OCD have the PANDAS subtype (25 children per 10,000)
- Difference:
  - PANDAS onset is quick, OCD slow
  - PANDAS associated with strep throat
  - Many children with PANDAS have tics
  - Children with PANDAS may have NEW problems with fine motor skills, math or other academics

# RESEARCH ON PANDAS TREATMENT

## Medical

- Steroids
- IVIG
- Plasmaphoresis

## Counseling (to treat OCD)

- Cognitive-behavioral: most effective
- ERP (exposure and response prevention)
- \*\*Thought patterns: "Thought stopping"
- Medication in conjunction with therapy
- Self help: medication, exercise, journaling, distraction

# WRITING PROCESS: OUTLINING

1

- I first needed to have a basic story idea
- I had several aspects that I wanted in the story and not into the story

2

- I wanted:
  - Cognitive behavior therapy
  - 2 children, one with and without PANDAS
  - One child to learn more about PANDAS

3

- I didn't want:
  - The story to be so informational that the child would lose interest
  - Similar to other stories written about PANDAS or OCD



## FINAL IDEA

- One idea was that Dave would learn what is happening in Charlie's brain similar to a "Magic School Bus" book
- Another was that he would receive therapy from a therapist (too similar to "Mr. Worry")
- FINAL IDEA:
  - Dave would visit Charlie's mind in a "Alice in Wonderland" sense. He would try to fight the PANDAS and realize how hard it was. He would learn that the best thing that he could do is to support his friend and just be a good friend.

## ILLUSTRATIONS: PROCESS

### Thumbnails

- I first drew thumbnails of each page.
- I then redrew them on large pieces of paper

### Sketches

- I copied the pages through a window to make two copies.
- I then cut out the pieces to make stencils for the fabric.

### Fabric cutouts

- I cut out the fabric pieces and laid them out on the sketches.
- I glued the pieces onto large sheets of paper.

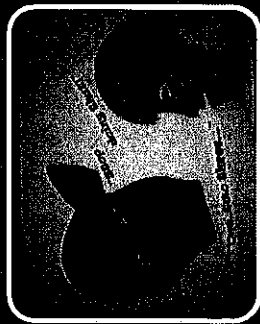


# FINAL ILLUSTRATIONS



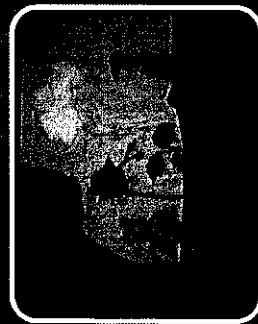
## Title Page

- I wanted to show how overwhelming the PANDAS was.
- I wanted to intrigue the reader with the title.



## Dave doesn't understand

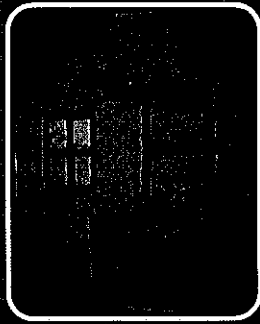
- To introduce both characters
- The illustrations look better when larger



## Dave goes to Capernia

- To show that Capernia was not real (Gillis, plants)

## ILLUSTRATIONS CONTINUED...



### Gillis and his home

- To show the despair of Gillis and the hope of Dave.



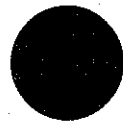
### The PANDAS

- To show that the PANDAS was just the names of a creature

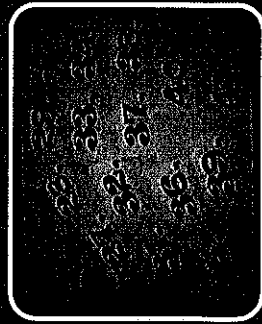


### Counting

- To show what is being rehearsed in Charlie's head.



## ILLUSTRATIONS CONTINUED...



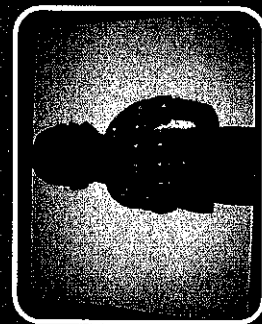
### Counting

- The exhaustion of Dave so he knew how exhausting it was for Charlie



### The PANDAS shrinks

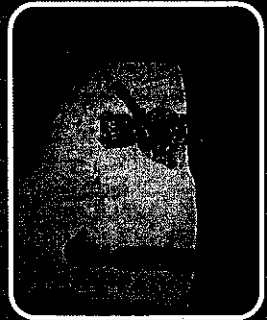
- To show that it was easier for Dave. The more he practiced standing up to the PANDAS



### Dave Cries

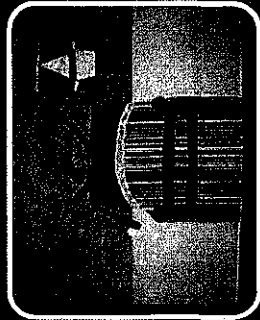
- He realizes that it is not as simple as overcoming the PANDAS just once

## ILLUSTRATIONS CONTINUED...



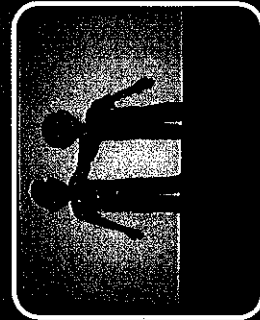
### Dave leaves

- The setting is similar to when he came.



### Dave is home

- Showing the joy of Dave. He is able to come to reality, but Charlie is not.

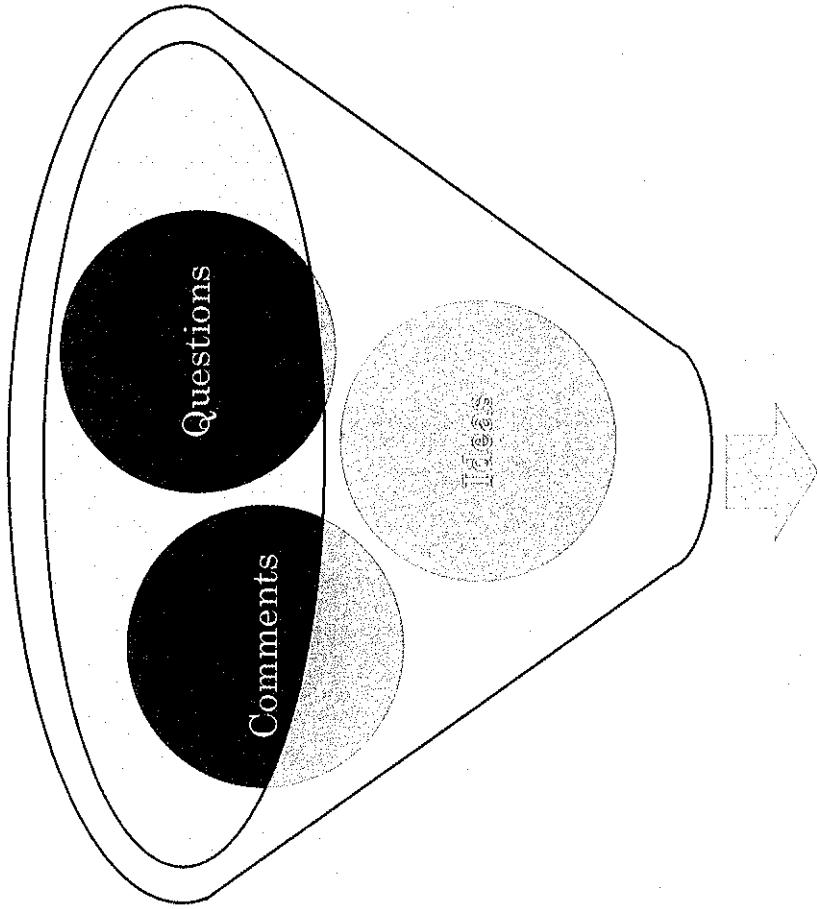


### Dave and Charlie

- Dave recognizes Charlie's struggle and the reader assumes that Dave will have more patience with Charlie

# FUTURE.....

- Publishing online through Amazon or other company
- Follow the Research
  - PANS: Pediatric Acute-Onset Neuropsychiatric Syndrome (Other infections besides strep throat)



**Discussion**

