

THE *Nephrotic Syndrome*

FOUNDATION

SUPPORT. EDUCATE. FIGHT.

NSF Finding Health Back-to-School Series Navigating School & 504 Plans

August 31, 2021

INTRODUCTIONS

DISCLAIMER

WHAT IS A 504?

TOOLKIT

Q & A

BREAKOUT SESSIONS

CLOSING

INTRODUCTIONS



Kimberly Smith
NS Parent & Teacher



Anju Lashkari, RN, CPNP
Health Educator
School Nurse



Andi Callaway
NS Parent

DISCLAIMER

- Material in this presentation based on individual experience and private research. It is designed to serve only as a general resource for awareness and discussion purposes. Information provided in this presentation should not be taken as complete, nor acted on without further verification or research.
- In addition, significant differences exist depending on state, school district and individual school.
- Opinions expressed in this session and on the following slides represent only those of individuals and not those of NSF or other related institutions.

WHAT IS A 504 PLAN?

- Blueprint or plan for how the school will provide support and remove barriers for a student with a disability.
- Similar to an IEP (Individualized Education Plan) but health related.
- Provides services and changes to the learning environment to enable students to learn alongside their peers.
- Provided at no cost to families.
- Governed by Section 504 of the Rehabilitation Act of 1973.

WHO IS ELIGIBLE?

- A child who has *any* disability. Section 504 covers a wide range of struggles in school. The disability must interfere with the child's ability to learn in a general education classroom.
- Section 504 has a broader definition of a disability than an IEP. (It says a disability must substantially limit one or more basic life activities. This can include learning, reading, communicating, and thinking.) That's why a child who doesn't qualify for an IEP might still be able to get a 504 plan.

WHO CREATES THE 504?

- A 504 plan is created by a team of people who are familiar with the child and who understand the evaluation data and special services options.
- This might include:
 - Child's caregiver / parent
 - School nurse, staff and / or principal
 - General and / or special education teachers

HOW DO I INITIATE A 504?

- Just ask!
- Speak to your school nurse and / or office administration.
- A doctor's note is not required to establish a 504 plan, however, it can be helpful.
- Examples can be found on our website under 'Finding Health'.

SAMPLE DOCTORS NOTE - #1

To Whom It May Concern:

██████████ is a ██████████ with Nephrotic Syndrome which requires high dose steroids off and on for flare ups. Common side effects of high dose steroids are cognitive, lack of focus and memory issues. Please modify his school curriculum with a 504 plan, as is deemed educationally necessary to accommodate his current medical difficulties.

Please feel free to call or write if you have additional questions.
██████████

SAMPLE DOCTORS NOTE - #2

To Whom It may Concern,

██████████ has been seen in my office on 8/9/2017 for her chronic health condition of Minimal Change Nephrotic Syndrome. In returning to school, she needs the following accommodations:

- 1) no PE class for a year
- 2) may miss school more often and needs to be given time to make up her missed work
- 3) needs to be able to use the restroom as needed and may need to take bathroom breaks during class sessions
- 4) can be late for lessons due to the symptoms
- 5) needs extra time to travel between classes
- 6) should not sit near sick people as she is on immune suppressant medication

504 TOOLKIT

- Go to www.nephroticsyndrome.foundation.org 'For Patients / Finding Health / Past Sessions'
- Resources:
 - Sample 504 Plan
 - Sample "Meet my Child"
 - Sample "Back to School / Class Announcement"
 - Sample Doctor Note with Justification for 504

SAMPLE 504 PLAN

- Sample only - specifics will depend on child, school and situation
- Elementary School - typically heavily focused on germ management and communication, with accommodations for missed school, etc.
- Middle School - still a focus on germ management and safety, but trends toward self-advocacy and academic accommodation
- High School - highly focused on testing and academic accommodations

“MEET MY CHILD”

- “Meet My Child” Document designed to give a short summary to those with limited time or attention
 - Short, sweet and to the point - focus on “how can you help”
 - Attaching a picture helps teachers identify your child and make a deeper connection from the start
 - Useful for ‘specials’, sibling teachers, sports coaches, troop leaders, substitutes, etc.
 - Make it one page!

“BACK TO SCHOOL / CLASS ANNOUNCEMENT”

- Example wording for use at Back-to-School Night or other in person introductions
 - Focus on communication, connection and compassion
 - Low pressure approach yielded very positive results for us!
 - Specifically state ‘non-contagious’
 - Relevant for sibling classes as well
 - We sent via email as a follow up after meeting parents at Back-to-School Night

OTHER TOOLS, STEPS & TIPS

- Handwashing demonstration at beginning of year
- Specific letter sent to classmates / grade-level about immunosuppressed child and importance of illness policy
- Communication of school illness policy to all parents at beginning of year and at start of flu season
- Education - World Kidney Day - March 10th, 2022
- Chronic illness form
- High-schoolers - pre-format email for when not feeling well
- In-person meeting with teachers extremely beneficial
- Work with your team!

Q&A

- Parent suggestion - second set of books / materials and specific parameters on when missed work will be sent home / communicated.
- Do we let parents of classmates know about diagnosis / that he is currently immunosuppressed? Does that cause issues with school-mates when someone is moved to accommodate?
- School preventing parent from speaking at Back-to-School night, citing HIPPA.
- Impact of COVID on 504 Plans?
- Online learning pros and cons?
- Open Q&A

BREAKOUT SESSIONS - 10 min

- Connect with others with kids the same age.
- Get to know one another!
 - Where do you live (roughly)
 - Child's age / grade
 - Biggest challenge or success with school
- Feel free to share contact information in chat or we can help facilitate (100% optional)

CLOSING & WRAP UP

- Feedback and suggestions welcome - email us!
andi@nephroticsyndrome.foundation.org or
bryn@nephroticsyndrome.foundation.org
- Requests or suggestions for future Finding Health topics?

Thank you for being here!
Your involvement & participation helps all of us!

