Advocacy 101

Amelia Williams
Young Adult Rare Representative, The EveryLife Foundation
PRESENTATION TOPICS

ABOUT ME

KEYS TO ADVOCACY

PERSONAL PATIENT ADVOCACY

COMMUNITY PATIENT ADVOCACY

Q & A
Amelia Williams
West Lafayette, Indiana
B.S. of Public Health
Purdue University
Elementary School Paraprofessional
Co-founder of In RARE Coalition & Leader of Indiana RDAC Movement
Pursuing MPH/PhD
Research Focus: Child Maltreatment Prevention for Disabled Children

The EveryLife Foundation
YARR Speaker’s Bureau, YARR Leadership Academy, Rare Disease Week on Capitol Hill x2, Rare Across America
MY STORY

PATIENT
MY STORY
ADVOCATE
KEYS TO ADVOCACY

**KNOWLEDGE**
- What are you asking for?
- What outside effects will it have?
- What resources does your ask require?
- Who can help you achieve your goal?
- What alternatives may be possible?
- What are possible objections to your ask?

**ASSERTIVENESS**
- Are you willing to ask for your needs?
- What can you do to stand up for yourself?
- What resources and supports do you need to stay calm, focused, and confident?

**PERSISTENCE**
- Are you willing to keep going in the face of resistance?
- Do you have a plan for when you meet resistance?
- How important is your ask to you?
- What resources are you willing to dedicate to that?

**RESPECT**
- How will you stay true to your values even when you face obstacles?
- How can you respectfully disagree with others while still asserting yourself?
KNOW YOUR RIGHTS

KNOW YOUR RESOURCES

TAKE ACTION

ADVOCACY PROCESS
You deserve to have your voice heard.

**HEALTHCARE RIGHTS**
- To be respected and treated with dignity
- Privacy & Confidentiality
- To seek a second opinion
- To receive copies of medical records
- To make decisions about the continuation/cessation of treatment
- To reasonable accommodation for disability

**RESOURCES**
- Patient Advocate (hospital system, nonprofit)
- Case Manager (insurance)
- Reliable online resources for information (Oley Foundation, YARR healthcare guide, Global Genes resource toolkits, government sites, etc.)
- ADA Advocacy Organization through state (search on NDRN website)
- Peers with similar health conditions

**ACTION**
- Bring a trusted friend or family member for support
- Be open about your symptoms, medical history, wants & needs, etc.
- Write out questions and concerns before appointment
- Take notes and document all interactions
- Follow up on documentation from visit
- Seek second opinions
EDUCATION RIGHTS

- Key Policy
  - Individuals with Disabilities Education Act (IDEA)
  - Section 504 of the Rehabilitation Act
- Rights
  - Reasonable Accommodation
  - Free Appropriate Public Education in least restrictive environment
  - Individualized Education Plan (IEP) /504 Plan/Individualized Health Plan (IHP)

RESOURCES

- American Association of People with Disabilities (AAPD)
- Mediation Session with Mediator
- State Department of Education

ACTION

- Be ready to provide documentation of medical conditions
- Maintain open channels of communication with school, doctors, and other providers
- Plan for the worst in terms of accommodations
- Example Accommodations
  - Plan for feeding tube/central line emergency
  - Nursing care
  - Extra time for meals & access to food at non-meal times

NOTE

Educational policy, rights, and procedures vary by type of education
- Public/Private
- Primary/Secondary/Postsecondary
EMPLOYMENT RIGHTS

- American with Disabilities Act:
  - Reasonable accommodation to access all parts of hiring and employment (MUST request)
  - Cannot ask about disability/medical conditions
  - Can ask if you can complete the job tasks with or without reasonable accommodation
- Cannot deny you employment, not give a promotion, or terminate you solely on basis of disability
- Confidentiality

RESOURCES

- Vocational Rehabilitation through your state
- Job Accommodation Network
  - A-Z of Disabilities and Accommodations: https://askjan.org/a-to-z.cfm
- Centers for Independent Living
- ABLE Account

ACTION

- Plan and execute conversations around accommodations
  - When
  - Where
  - With Whom
- Keep a record of requests and responses
- File a discrimination complaint w/ U.S. Equal Employment Opportunity Commission

**Same regulations do not apply to private small businesses with less than 15 employees**
RECREATION + COMMUNITY

“What we know matters but who we are matters more”
-Brene Brown

RIGHTS
- Rehabilitation Act of 1973
  - Prohibits discrimination against disabled students in school sports
- Americans with Disabilities Act

RESOURCES
- Adaptive Sports
- Patient Organizations
- Rehabilitation Hospitals
- Recreation Therapy

ACTION
- What types of activities do you enjoy? What activities are culturally important?
- What would inclusion look like and what accommodations are needed?
- Could recreation goals be included in IEP?
- Balance inclusion, connection, and belonging
- Connect with others to find resources

Never, ever underestimate the importance of having fun.
-Randy Strach

Rehabilitation Act of 1973
Prohibits discrimination against disabled students in school sports
Americans with Disabilities Act
COMMUNITY PATIENT ADVOCACY
ORGANIZATIONS

OLEY FOUNDATION
YOUNG ADULT RARE REPRESENTATIVES (YARR)
PATIENTS RISING
AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES (AAPD)
FDA PATIENT REPRESENTATIVE PROGRAM
GLOBAL GENES
RARE YOUTH REVOLUTION
YOUR CONDITION’S PATIENT ORGANIZATION
NATIONAL ORGANIZATION FOR RARE DISORDERS (NORD)
YOUR STATE’S RARE DISEASE ADVISORY COUNCIL (RDAC)
QUESTIONS?
Please submit to Zoom’s question feature!
THANK YOU

Feel free to reach out with any further questions!

- Amelia.winter.williams@gmail.com
- @amelia.winter.williams
- linkedin.com/in/awinterw