

PPMD Connect Conference 2018

Life After High School Panel

PAAC Group represented by:

Colin Rensch

Michael Counterman

Ben Dupree

Alex Toalson

Jenn Bauer

Parent **Project** **Muscular** **Dystrophy**
JOIN THE FIGHT.
END DUCHENNE.

Going to College

Alex Toalson

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Going to College: Application

- Before applying make sure you have information about services that the school provides for students with disabilities
- During the application process make sure that the school you are applying to is aware of your personal needs
- When accepted to the school be sure to register for services provided to students with disabilities
- After registering for services meet with the office providing the services to create an accommodation plan

Going to College: Accommodations

- When registering for classes each semester be aware of any accommodations you may need such as classroom and testing accommodations
- Be sure to inform the office that provides services to students with disabilities of the classes you are registered for so that they can help you with accommodations
- When classes begin meet with your instructors to find a time to meet and discuss accommodations and exam schedule
- After meeting with the instructor meet with the office providing services to finalize accommodations and exam schedule

Studying Abroad

Colin Rensch

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Study Abroad Opportunities

- Most colleges/universities offer study abroad opportunities ranging from 3 week to whole year options
- While not as long, the shorter trips are equally rewarding and present fewer logistical challenges (but not none)
- Ask around to determine which program best satisfies your interests and meets your needs
- Most colleges/universities have offices devoted to study abroad programs. YOU ARE NOT IN THIS ALONE!
- I took part in a 3-week program in Vienna, Austria in 2015
- Two friends (who were also my PCAs) accompanied me
- This arrangement was determined after speaking at length with the trip's faculty director, my dean, and my parents

Study Abroad Opportunities

- Mobility International USA (www.miusa.org) and Wheelchair Travel.org (<https://wheelchairtravel.org/>) offer great resources
- Since there are no int'l accessibility regulations, ask trip coordinators to provide photos or detailed info on hotel/apartment rooms, busses, sights, etc.
- Be prepared to problem solve as issues arise, but ask as many questions beforehand as you need to feel comfortable



Internships and Jobs

Michael Counterman

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What is an Internship?

- A program offered by an employer to potential employees
- Interns work part time or full time for a pre-specified period of time
- Internships are most popular with undergraduates or graduate students who work between 1-4 months to gain practical work or research related experience
- Are a great way to build your network, gain hands-on experience, improve your resume, and gain self-confidence!

Where to Look for Internships & Jobs

Internship Search Sites

Internships.com

Idealist.org

Experience.com

Indeed.com

LinkedIn

Job Search Sites

Indeed.com

CareerBuilder.com

Dice.com

Glassdoor.com

Google for Jobs

Idealist.com

LinkedIn.com

LinkUp.com

Important Skills Required for Jobs and Internships

- Communication
- Interpersonal
- Collaboration
- Time Management
- Adaptability
- Critical Thinking
- Research and Analysis
- Receptiveness
- Technical Proficiency

Tools Needed To Position Yourself As A Strong Applicant:

LinkedIn Profile
Resume
Cover Letter
References (teachers, former supervisors, volunteer work)

Tips for Success

Ben Dupree

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Stay Productive!

- Maintain a Professional Attitude **Even if You Aren't Employed**
 - Keep an updated resume.
 - A CV with a more complete list of accomplishments can be helpful as well. You can pull from this to tailor your resume to specific opportunities.
- Keep Yourself Organized
 - Keep a calendar and actually use it.
 - Keep a notebook and take notes on important phone calls and conversations.
 - Find a way to keep track of to-dos (**Don't Try to Remember Everything**).
- Don't Drop the Ball
 - Developing these habits takes a lot of work up front.
 - Once you've finished the initial push it takes a small amount of effort each day to keep up.
 - Eventually it becomes second nature.

Get Out There!

- Find Ways to Participate in Your Community
 - Volunteer at churches, hospitals, other community organizations.
 - A community doesn't have to be local.
- Make Connections When Possible
 - Keep contact information for people in areas relevant to your interests or professional goals.
 - You never know when it may be helpful later.
 - Personal business cards can be useful.

Family Planning

Jenn Bauer

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Family Planning

- Having a family is now a wonderful reality for people with BMD and DMD.
- We have many fine parents in our PAAC group. For example, Mario Damiani became a father last year, Kanch Randhawa is the father of three children and Jenn is the mother of a five year old daughter.
- Options for starting a family
 - Naturally
 - Could result in a BMD/DMD affected child or carrier
 - IVF (In-Vitro technology with Preimplantation Genetic Diagnosis)
 - IVF with PGD allows future parents to have embryos tested for the BMD/DMD gene mutation and carrier status.
 - Use embryos that are free of DMD/BMD mutation after testing.

PPMD's Genetic counselors are available to discuss these many options.

Parenting with a disability

- Becoming a parent can be an amazing and rewarding experience for someone with a disability.
- A good amount of physical help is needed when you bring a newborn home.
 - If you are unable to lift a child or complete childcare tasks, you will need to have the assistance of a family member, caretaker or nanny.
 - It will take a lot of support and coordination to take care of a baby but the reward is totally worth it.
- Once your child is 4 or 5 they will become your “special helper”.
- Children will have questions about your condition and it’s important to address them open and honestly.
- The child or children will witness your struggles but it’s important to ALWAYS keep a positive spin on it.
- Enjoy watching your child become a caring and empathetic person.