Parent Project Muscular Dystrophy
JOIN THE FIGHT. END DUCHENNE.

A GRANDPARENTS' GUIDE

Supporting Your Loved Ones Affected by Duchenne or Becker Muscular Dystrophy

LETTER TO THE COMMUNITY

Dear Grandparents,

When a child is diagnosed with Duchenne or Becker muscular dystrophy, it changes the lives of everyone who loves them. As a grandparent, you may find yourself experiencing many emotions at once—heartbreak for your grandchild, concern for your own child as they navigate this unexpected journey, and an overwhelming desire to help, even when you're not sure what to do. While you can't change the diagnosis, your love, support, and steady presence can make an extraordinary difference.

When my sons, Christopher and Patrick, were diagnosed with Duchenne muscular dystrophy, our family's world changed forever. Like so many parents, grandparents, siblings, and loved ones, we were overwhelmed with questions, uncertainty, and grief. We also discovered something equally powerful: the strength that comes from facing this journey together.

I founded Parent Project Muscular Dystrophy (PPMD) because I believed families deserved better—better care, better research, better treatments, and a community that understands. More than 30 years later, that mission remains the same. Today, PPMD is here to support every family affected by Duchenne and Becker muscular dystrophy with trusted information, resources, advocacy, and a community that will walk beside you every step of the way.

We created this guide especially for grandparents because your role matters. You are often the steady presence, the listening ear, the extra set of hands, the keeper of traditions, and the source of unconditional love that helps hold families together during life's most difficult moments. Whether you're learning about Duchenne or Becker for the first time, looking for ways to support your family, or simply trying to process your own emotions, I hope this guide provides comfort, practical guidance, and reassurance that you are not alone.

Thank you for being part of this community. Together, we have changed what is possible for families living with Duchenne and Becker, and together, we will continue working toward a brighter future.

With gratitude,

Pat Furlong
Founding President
Parent Project Muscular Dystrophy

UNDERSTANDING DUCHENNE & BECKER

WHAT ARE DUCHENNE & BECKER MUSCULAR DYSTROPHY?

Duchenne ("doo-SHEN") muscular dystrophy is the most common type of muscular dystrophy in children and causes muscles to become weaker over time. It affects about 1 out of every 5,000 male births.

Duchenne and Becker muscular dystrophy are on a spectrum of muscle diseases known as dystrophinopathies that are caused by a change in the dystrophin (DMD) gene. Changes to this gene, called genetic variants, can lead to differences in the amount, size, or function of the dystrophin protein. The dystrophin protein is critical for maintaining muscle cell structure and function. Dystrophin acts as a "shock absorber" that allows muscles to contract and relax without being damaged. Without the dystrophin protein, muscles are not able to function or repair themselves properly.

The term "dystrophinopathy" refers to the spectrum which includes both Duchenne and Becker. You can think of Duchenne and Becker as different ends of this spectrum. Becker muscular dystrophy has many similarities to Duchenne but can be slower progressing.

PPMD's mission and work extends to the entire spectrum, but sometimes you will hear or read references to all dystrophinopathies as "Duchenne" for simplicity.

Symptoms & Progression

Duchenne & Becker both progress slowly over time. Muscle loss in Duchenne typically begins in childhood, with loss of strength, function, and flexibility. Many times weakness in the hips, thighs, shoulders, and pelvis are first noticed. As children get older, muscle weakness becomes more prominent in the arms, lower legs, and torso. Because there is also an absence of dystrophin in the muscles of the heart and lungs, heart function and breathing are also affected. In addition, some people can have differences in learning and behavior, resulting from a lack of dystrophin in the brain. Individuals with Becker may have later onset of symptoms and/or slower progression.

Because this diagnosis affects multiple systems in the body, individuals should be seen by a comprehensive multidisciplinary clinic or Certified Duchenne Care Center.

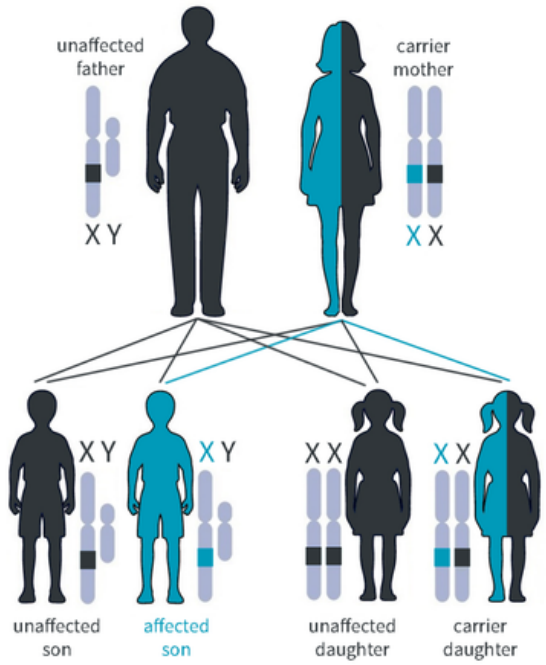
Keep in mind that Duchenne & Becker progress differently in everyone. Even siblings with the same genetic variant (genetic change) may have a different progression of symptoms.

WHY DOES MY GRANDCHILD HAVE DUCHENNE/BECKER?

Duchenne and Becker muscular dystrophy are caused by changes in a single gene in our bodies called the DMD gene. Duchenne & Becker can be passed from parent to child, or it can be the result of a new, spontaneous genetic variant (genetic change). In fact, about one out of every three cases of Duchenne is caused by a completely new genetic variant in the family. About one out of ten cases of Becker are due to a new variant. Duchenne and Becker can affect anyone, across all races and cultures.

In order to understand how Duchenne or Becker can occur in a family, it is helpful to understand some basic genetics. We as humans have 23 pairs of chromosomes, or 46 total, in every cell of our body:

- 44 autosomes (pairs 1-22)
  - Every child inherits one copy of each autosome from each parent
- 2 sex chromosomes (pair 23)
  - Females usually have two X chromosomes (XX), one from each parent
  - Males usually have one X and one Y chromosome (XY), the X chromosome from their mother and the Y chromosome from their father



The DMD gene is found on the X-chromosome, and males typically only have one X chromosome. So if they have a DMD gene variant, there is no backup to provide fully functional dystrophin protein, which is why Duchenne & Becker primarily affects males.

When females inherit a DMD gene variant, they typically have a second X chromosome and second copy of the DMD gene to serve as a "backup", which is why those females are often referred to as carriers. However, because females have health risks associated with DMD gene variants and may exhibit a varying ranges of symptoms of Duchenne or Becker, they may be referred to as "manifesting carriers" or females with dystrophinopathy.

Thousands of different genetic variants have been reported in the dystrophin gene. **It is important to keep in mind that no one causes genetic variants to occur or be inherited, and they cannot be prevented.** Each of us carries variants in some of our genes, though we usually do not know it.

Does the rest of my family need to be tested?

Mothers of individuals with Duchenne or Becker may want to undergo carrier testing. This is important for women to better understand their own health risks, including heart changes and skeletal muscle weakness, as well as understanding their chance to have children with Duchenne or Becker. By being aware of their own genetic status, women can make informed decisions regarding future pregnancies, be aware of potential health implications and complete the necessary health screening that is recommended for carriers.

If a woman is found to be a carrier, their relatives on the maternal side should consider testing as they too may be carriers. This most commonly includes grandmothers, aunts, sisters, etc. Any siblings of a person with Duchenne or Becker should be offered genetic testing, regardless of their mother's carrier status. Genetic counselors can help identify which family members may consider testing and how to pursue testing. Individuals suspected to have Duchenne, Becker, or to be a carrier, as well as their family members, are eligible for PPMD's sponsored testing program, Decode Duchenne, to access no-cost genetic testing.

It's important to remember that if someone is found to be a carrier, feelings of guilt are common. However, no one has control over which copies of their genes are passed on to their children. It's important to stress: nothing during pregnancy or lifestyle caused this genetic change.

PROCESSING THE DIAGNOSIS FOR THE WHOLE FAMILY

Every Person Processes Differently

Getting a diagnosis of Duchenne or Becker is life altering for families. It might bring forth emotions of grief, sadness, guilt, and even anger. Parents often grieve the loss of the future they imagined for their child (also called anticipatory grief) all while trying to quickly take in new information and make decisions around care and treatments. Some parents will dive right into research and treatments, while others will take time accepting the diagnosis. Remember, there is no right way to grieve or cope and everyone will do so in their own way and at their own pace.

Receiving the News as a Grandparent

As a grandparent, with or without a known family history, it is normal to experience shock, sadness, disbelief, and a variety of other emotions following a diagnosis of Duchenne or Becker within the family. Grandparents not only grieve for their grandchild, but also for their child and their family. Grandparents may want to "fix" this very difficult reality, even though this is something that cannot be changed. It can be especially difficult to navigate your own feelings, while trying to be available for your child and their family. Seeking outside support, such as counseling, can be beneficial for all members of the family.

Talking to Friends and Extended Family

Following the diagnosis, conversations can be hard and uncomfortable for everyone. Grandparents often play a key role in talking to and educating extended family members & friends about Duchenne and Becker. You can help by sharing clear, simple explanations about the diagnosis, its progression, and how family members can help. Resources like Parent Project Muscular Dystrophy can help with these explanations. Encouraging empathy, understanding, and patience in relatives can reduce stress for your grandchild and their parents.

Keep in mind that everyone's reaction will vary and not everyone will understand. Those people who do understand will be your greatest lifelines in this journey.

PPMD for YOU

Schedule a one-to-one meeting with the PPMD team for personalized support and resources. Visit www.parentprojectmd.org/ppmd-for-you

SUPPORTING YOUR FAMILY

Supporting Your Adult Child

It may be difficult knowing how to support your adult child without feeling like you are overstepping. Your adult child will feel a mix of emotions throughout this diagnosis and at times, some emotions may be misdirected. You may be the "safe" person for your child and their emotions and anger may be directed at you, as they know you won't judge them. They may say things that are hard for you to hear, but maintaining your relationship is of the utmost importance so that over time, you can continue to be their steady support. Listen without judgement, offer practical assistance, and let your child know you are a part of their team and support system. Open communication is critical. You also want to recognize when to set healthy boundaries. You may disagree with some of your child's decisions or parenting styles, but respecting their choices is important as there is no one right way to navigate this diagnosis.

Supporting Your Grandchild with Duchenne or Becker

While adults have their own way of coping with this diagnosis, children often already know something is different with their body before a diagnosis is made. They may have questions for you as their grandparent, and it's important to be honest with them and provide answers at an age appropriate level. Be sure to discuss with their parents any hard questions or topics that come up so everyone is consistent in their language and answers. For example, some families may prefer to use the term "special muscles" at a young age while others may prefer to use Duchenne or Becker right away.

Supporting Siblings

When a child gets diagnosed with Duchenne or Becker, naturally the attention from parents shifts primarily to that child and their complex medical needs. This can oftentimes leave siblings feeling left out, which can lead to behaviors or feelings of resentment. As a grandparent, you are in a unique position to help provide that support to siblings whether you live nearby or far away. This can include spending dedicated 1:1 time with the sibling(s), attending extracurricular activities, regular phone calls and check-ins, etc.

Supporting Other Children and Grandchildren

Family dynamics may be hard at times and this diagnosis can have a ripple effect on other family members. If you have other adult children, they may also have strong reactions to this diagnosis and possibly perceive that you are giving more time and attention to the family with the Duchenne or Becker diagnosis. Be diligent in keeping communication open with the entire family and make an effort to be available for your other children and grandchildren as well. By being aware of these potential feelings, it can help you navigate and alleviate potential worries.

"DO EVERYTHING IN YOUR POWER TO KEEP COMMUNICATION OPEN AND INCLUDE ALL OF YOUR CHILDREN AND GRANDCHILDREN IN FAMILY ACTIVITIES WHEN POSSIBLE. SPREAD YOUR TIME AS EVENLY AS POSSIBLE WHILE RECOGNIZING THAT THERE MAY BE MORE NEED FOR YOUR GRANDCHILD WITH DUCHENNE OR BECKER"

RECOGNIZING A GRANDPARENT'S ROLE & CARING FOR YOURSELF

Every parent wants a life of joy, peace and happiness for their children and family. A diagnosis like Duchenne or Becker can feel like it changes that vision. Grandparents grieve deeply for their child and their grandchildren as they see what their child must navigate, along with the struggles their grandchild may endure. At the same time, grandparents may feel pulled in many directions—wanting to be strong and supportive for their family while also working through their own emotions. It is important to acknowledge your feelings and have your own support system so that you can take care of yourself and be available to your children & family.

Caring For Yourself

Through all of the support you offer to your grandchild, adult child and other family members, remember to take time to care for yourself. This diagnosis can be emotionally demanding and it's okay to take time to focus on your emotional well being. Therapy, support & advocacy groups, and hobbies are all ways to make sure you are the best version of yourself.

PPMD'S GRANDPARENTS GROUP

PPMD's Grandparents Group, which meets virtually 6-8 times a year, is a great way to find support for yourself and your family. This group provides information, community, and connection with others who understand and share in what you and your family are going through. To join PPMD's Grandparents Group, email nicole@parentprojectmd.org to be added to our email list about upcoming meetings.

PRACTICAL WAYS GRANDPARENTS CAN HELP

As a grandparent, you may feel lost at times and not exactly sure how you can help your loved ones. Keep open communication with your adult child and ask them how they would like you to be helpful. There are many practical ways grandparents can be supportive to their children and grandchildren throughout this diagnosis. Every family is different and the needs may change over time, so it's important to be flexible in how and when to offer your help. Below are some potential ways to provide support from both near and from afar:

Phone calls and support

Throughout the diagnosis, parents often go through the cycle of grief, repeatedly. Even if there are times when you aren't sure what to say or do, just by being there and offering a listening ear can provide tremendous support to your loved ones. Whether you live nearby or far away, knowing they can count on you is immensely supportive to your children and grandchildren.

Create a welcoming and, if possible, accessible home

Having a home that is welcoming and barrier free can remove great amounts of stress for families. While it may not be possible to make your home accessible, see if you can find ways to make it easier for your grandchildren to visit you. For example, keep toys & games on the main level of the house so your grandchild doesn't have to go up and down the stairs multiple times while playing.

Offer to research treatments and clinical trials

A diagnosis of Duchenne or Becker brings forth a whole new language of medical & research terms. It can be daunting to try and sift through & understand all of the new information. Ask your child if they would like you to help research some of these things & share information that is applicable. This can save time and energy so that they can focus on their family and the things that are needed in the moment. However it's important to understand before diving in, if this is an area of support they want and need.

Offer to attend medical appointments as back up support

If you are local, offering to attend medical appointments with your child and grandchild could be extremely helpful. Clinic days are long and overwhelming. Having a support person there to help take notes, keep the children occupied, or just being there so they know they are not alone can make a huge difference. If you are not local, you can always offer to listen in on the phone (if your child would like) to help gather information & talk through things afterwards.

Review local resources and support programs

There are different resources available in every state. Many times families do not know what exists until they go looking for it. Have a discussion with your child to see if there are ways you can divide up reviewing these resources to reduce the amount of time the parent has to be researching. This can be anything from state medical benefits to accessible parks in the area.

Offer to watch children, provide meals, or transportation

If you are local, offering to watch the children, providing meals and offering transportation are tangible efforts that can be extremely helpful for families. Managing the rest of the family as well as this diagnosis brings a laundry list of "to-do's" and taking something off the list can help lighten that load. If you do not live near your loved ones, you can send door dash meals or gift cards to make life at home just a little bit easier.

BENEFITS & FINANCIAL PLANNING

There are different support programs that can help people living with Duchenne or Becker with health insurance, disability benefits and educational/vocational resources. Grandparents can offer to help by learning about trusts, financial support, and/or future planning to protect long-term wellbeing for their grandchild. Providing support to parents as they navigate these programs and fill out applications can alleviate some of the stress. Families should always meet with an experienced attorney and/or financial advisor to ensure any financial programs are well understood and managed. Some important terms to be familiar with:

Medicaid & Waiver Programs

Medicaid is a government health insurance program funded by both federal and state governments. It helps cover medical costs for people with limited income and assets. Each state's eligibility is different and may include waiver program options like Katie Beckett/TEFRA or Home Based Community Services (HCBS) for children with disabilities. Under these programs, a state can waive certain eligibility criteria, providing coverage for individuals who might not otherwise be eligible for Medicaid.

Because these programs vary by state, the local Department of Health and Family Services (state Medicaid services), and/or a clinic social worker can talk through what may be appropriate for your grandchild. Learn more about Medicaid programs here

Special Needs Trusts

Special Needs Trusts are a legal tool for people with a disability to receive income without losing eligibility for benefits such as Medicaid. These trusts can cover expenses like medical & dental care, therapy, equipment, quality of life expenses and services not otherwise covered by medical insurance. Grandparents can support by helping establish a trust, contributing to it, and encouraging families to consult an experienced attorney.

529 ABLE Accounts

ABLE (Achieving a Better Life Experience) accounts are an option for saving money specifically for people with disabilities. These accounts allow families to save money for qualified expenses, such as education, housing, and transportation without affecting eligibility for benefits like Medicaid or SSI. Grandparents can help by learning how these accounts work, contributing to them, or helping manage them responsibly.

Future Planning

Grandparents who want to leave a financial inheritance to a person with Duchenne or Becker may include specific language in their will (or an addendum to an existing will) directing the sum to be placed in a "to be established trust". Speak to a financial advisor or attorney before setting these up to discuss appropriate timing and ensure protection of eligibility for benefits.

WHAT'S NEXT? ADVOCACY, COMMUNITY & IMPACT

There are many different ways to support your family through this diagnosis, but there are also ways you can make an impact for other families as well. Below are some ways other grandparents have found fulfillment in supporting both their loved ones & the larger Duchenne & Becker community.

Become an Advocate

As the need for muscular dystrophy research & care grows, the need to educate legislative officials - federal, state & local - grows with it. Grandparents can advocate for their grandchild and others by joining PPMD in Washington DC at our Annual Advocacy Conference or signing up to be a PPMD Advocate from home. By becoming an advocate, you will receive emails throughout the year about how you can take action through online action alerts right from home, as well as hear about opportunities to advocate in person with your elected officials. Sign up to be a PPMD Advocate at https://form.jotform.com/Parent_Project/become-a-ppmd-advocate

Attend a Community Event

PPMD hosts community events throughout the year including PPMD Together meetings, which are smaller regional gatherings, as well as PPMD's Annual Conference every summer. This is a unique opportunity to learn more about Duchenne & Becker care, research and advocacy and meet with other families, industry partners and clinicians from all over the country. Attending these in-person events can provide a sense of support to you as a grandparent as well as an opportunity to offer to bring information back to your loved ones. To learn more, please visit https://www.parentprojectmd.org/get-involved/attend-events/

Host a Community Fundraiser

Hosting a fundraiser is a meaningful way to raise awareness about Duchenne or Becker in your community, support PPMD's mission and make a difference for your grandchild and the larger Duchenne & Becker community. From garage sales to restaurant fundraisers to golf outings, PPMD can help support you build something you are passionate about! To get started, fill out this form and we'll schedule a call to discuss your ideas https://form.jotform.com/Parent_Project/diy-fundraising

Make a Monthly Gift

Another way to make a lasting impact and provide steady support for PPMD's mission for this community is by becoming a monthly donor. You can make a donation on PPMD's website in recognition of your grandchild by choosing "Monthly" as the recurrence, and your gift will be made automatically each month. This ongoing support will help PPMD continue our programs & services for the Duchenne & Becker community now and in the future. Visit www.parentprojectmd.org to set up a monthly donation.

Corporate Matching & Workplace Giving Programs

If you are still working, your employer may be able to help. Many companies offer matching gift programs for their employees, and in some cases, retired employees as well. When you make a gift to PPMD, use our online tool to find out whether your employer provides matches and submit the required forms or paperwork to your employer. PPMD will take care of the rest.

Planned Giving

Structuring your long-term financial plans with PPMD in mind can allow you to make a gift in your loved ones honor while meeting your personal planning goals. There are a variety of gift planning options with special advantages, such as increased tax benefits. There are numerous types of planned gifts that generally fall into three categories: gifts in your will or living trust, gifts that produce income, and simple ways to give through beneficiary designations. Gifts of all sizes are meaningful and can enable you to leave a legacy that lasts. Contact your financial advisor or attorney about how to include PPMD in your long-term financial plans.

A diagnosis of Duchenne or Becker impacts everyone in the family differently. But you are not alone.

As grandparents, you play a pivotal role in your family. There is no one "right" way to help, but your unwavering love and support can make a significant impact in your loved ones journey. And when you feel stuck, lean on PPMD and your support system. We will get through this together, because together we are stronger.