
Emergency Care

Emergency room staff may not have experience caring for people with Duchenne, so it is helpful to bring emergency information with you that is specific to Duchenne. This includes information on anesthesia, fracture management, oxygen, steroid stress dosing, and more. PPMD has this information available on their website ([ParentProjectMD.org/Emergency](https://parentprojectmd.org/emergency)) to print or it is available within their free Apple or Android App ([ParentProjectMD.org/App](https://parentprojectmd.org/app)).

- Have emergency information, either on a card or a mobile app, with you at all times.
- Have a summary of your last NMS visit, provided by your NMS, with you at all times. These will include the diagnosis, all medications, recent test results (including heart and lung function), and any reoccurring medical problems that you may have.
- Take any equipment that you use and your medications with you to the emergency room or hospital.
- Contact your NMS if you need to go to the emergency room or hospital for any reason.
- If you are taking steroids, have a copy of the PJ Nicholoff Steroid Protocol (available at: [ParentProjectMD.org/PJ](https://parentprojectmd.org/pj)) which provides information on preventing adrenal insufficiency and indications for stress dosing of steroids.
- Take your power of attorney form to the hospital with you if you are over age 18.

Primary Care

Primary care providers (PCPs) are doctors, nurse practitioners, or physician assistants who specialize in pediatrics, family, or internal medicine. This provider should work closely with your NMS.

- Continue seeing your primary care provider for routine visits, including well checks, minor illnesses, and immunizations.

Information and Support

If you have not already done so, it may be helpful to get in touch with an organization dedicated to helping individuals with Duchenne and their families.

- Parent Project Muscular Dystrophy (PPMD): [ParentProjectMD.org](https://parentprojectmd.org)

Notes