



## Revealing new photographic series highlights the plight of those living with a rare, genetic and terminal disease

*Rare Beauty: Faces of MPS* photo series released this International MPS Day



**15 May 2018:** Today, those living with a rare, genetic disorder, known collectively as mucopolysaccharidoses (MPS), have told their stories as part of a new photo series, which aims to raise awareness for this group of conditions. Those living with MPS are missing a specific enzyme which breaks down substances in the body, resulting in many debilitating physical symptoms, as well as in some cases, effects on the brain.

The new photo series released today, on International MPS Day, marks the launch of a new campaign by the Australian MPS Society (MPS Society) – which aims to raise awareness, support and understanding for those Australians living with MPS and tells the stories of some of the families involved in the MPS community. This year's campaign focused on the Brisbane-based MPS and mucopolipodosis (ML) families.

“For those living with MPS, many have had multiple surgeries, some receive treatment and spend large amounts of time in hospital, or require 24-hour care at home, but there is no cure,” says Vanessa Ede-Scott, Operations Manager for the Australian MPS Society.

“It is our hope that this series generates widespread awareness and support in the general community for those living with MPS, and the everyday challenges that each of these families’ face.”

For Michelle Morrice, whose son Alec lives with MPS III, and is one of the patients featured as part of the *Rare Beauty: Faces of MPS* photo series, raising awareness for MPS is of the utmost importance.

“For Alec, there is no treatment, no cure. We just have to watch him fade. We really want Australia to know that those living with rare diseases, like MPS, need help to spread awareness, to fund research and to institute tolerance of diversity.”

For Samantha Prior, 32, living with MPS VI, being a part of the photo series means raising awareness for MPS, and reaching others within the community.

“When I was diagnosed with MPS, Google didn’t exist. So now, it’s incredibly important to me that I can help those who are newly diagnosed, or are needing help, to navigate all the information that is out there,” says Ms Prior.

The MPS Society is today calling for more funds to be raised for research, as well as to support those families living with MPS. More information on the Australian MPS Society can be found at their website: <https://www.mpssociety.org.au/>

Get involved on social media by sharing the images from the series, and using the hashtag **#MPSrarebeauty**.

The photo series is available to view at: <https://www.mpssociety.org.au/>

The *‘Rare Beauty: Faces of MPS’* campaign was made possible through funding and support from BioMarin Australia [www.biomarin.com](http://www.biomarin.com)

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