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Sent: 19 July 2024 13:30
To: dghs@nic.in
Cc: swasticharan.l@nic.in; ratna.devi@dakshamahealth.org
Subject: Please include Neurofibromatosis (NF) in NPRD

Prof. (Dr.) Atul
Goel

19.07.2024

Director General of Health Services
Ministry of Health and Family Welfare
Government of India

Subject: Request for Inclusion of Neurofibromatosis Type 1/Type 2 (NF-1/NF-2) in National Policy for Rare Diseases, 2021

Respected Sir,

My name is Dr. Sudhir Kumar Gupta, 58, M.Sc, Ph.D. I have worked in the private sector in responsible positions both in India and abroad. As a father of a child with NF-1, I am writing to you to request the inclusion of genetic disorder Neurofibromatosis (NF) in the National Policy for Rare Diseases (NPRD) of 2021.

The Government of India and the Directorate General of Health Services have implemented various measures to support individuals suffering from rare illnesses, particularly through the NPRD 2021. However, I wish to draw your attention to another rare disease that requires government attention and support—Neurofibromatosis (NF). This genetic disorder predominantly manifests as Neurofibromatosis Type 1 (NF-1) or Neurofibromatosis Type 2 (NF-2), with NF-1 being more prevalent.

Despite its prevalence, NF-1 often goes undiagnosed or misdiagnosed due to inadequate medical awareness and infrastructure, leading to significant challenges for patients and their families. Individuals with NF may experience a wide range of symptoms like bone abnormalities, vision problems, deformation of body/ bones, skin pigmentation, multiple tumours growing on nerves throughout the body and at times life threatening tumours on vital organs. Individuals have to undergo many physical challenges, cope up with learning disabilities, emotional challenges such as low self-esteem, social anxiety and future insecurity. It is essential for NF patients to receive emotional, financial and medical support to help them cope with these challenges and Government has a vital role to play in this.

Including NF in the national policy for rare diseases is crucial to ensure that individuals affected by this condition receive the care and support they need. Recognizing NF as a priority within the national policy would improve access to specialized medical care, facilitate research and development initiatives, and raise awareness about the impact of NF on individuals and families.

As a father of a 16-year-old with NF-1, our struggle has been daunting and demanding. While there is significant attention and support for the NF population in developed countries like the US, EU, and Australia, there is practically none in our country. A few years ago, I supported a hospital in Mumbai from CSR funds to open its first NF clinic in the country. Recently, I launched the website www.Bharatnffoundation.org to support and focus on the needs of this population and a program was organised for NF patients at SRCC Children hospital in Mumbai along with the team of competent doctors (https://www.linkedin.com/posts/dr-sudhir-kumar-gupta-7904881_the-multi-disciplinary-

[neurofibromatosis-activity](#)). I am also in the process of forming a non-profit organization to raise funds to support this community. My main motivation is to help this fraternity and other parents so as they do not have to undergo the same ordeals that we have faced.

Support from policymakers in this context would be invaluable, and I earnestly request you to consider including NF in the national policy for rare diseases. By doing so, we can demonstrate our commitment to supporting all individuals affected by rare diseases and ensure they receive the care and support they deserve.

If you need any more information from me as a parent and as a crusader for this cause, I will be more than happy to represent the case and make a presentation to you.

We are also in contact with other non-profit organizations in the healthcare sector, such as Dakshama Health, represented by Dr. Ratna Devi, to garner necessary attention and support for the NF cause.

Sir, I thank you in advance for your kind attention to this matter. I look forward to your prompt response and action on this matter of national importance.

Sincerely,

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