

A Message from the Medical Director

For over a decade, The Progeria Research Foundation has been working towards discovering the cause, treatment, and cure for Progeria. We've seen Progeria move from obscurity, to gene finding, to treatment trial within that time. Each day that passes, families and their health care providers search for guidance on how to increase quality of life for children with Progeria. With their beautiful smiles and their incredible personalities, we all want children with Progeria to live their lives to the fullest. I sincerely hope this guide provides some assistance in that common goal.



With the input of many caring contributors, we've compiled this first edition information handbook. Thank you to all who devoted their time and expertise so that this handbook could be developed. Most of all, thank you to the children who inspire the rest of us every day.

Concept

This handbook is intended to help families of children with Progeria at all ages and stages of development and disease. There are sections that speak directly to families, and there are more technical recommendations for health care providers. These are intermingled within each chapter. You will also note some repetition between sections. Because we are making each section available as a stand-alone document on the PRF website, some repetition is necessary.

Updates

Even as we write this first edition of the Progeria guide to clinical care, our understanding of Progeria and the needs of the children, their families, and health care providers is growing exponentially. We designed the handbook with a binding that allows you to add and replace information as new chapters are written in the future. In this way, you will be as up-to-date as possible on care recommendations and research programs for children with Progeria.

The Progeria Research Foundation strives to be the driving force worldwide to:

- Discover the cure for Progeria
- Develop treatments for children with Progeria
- Provide programs that push the field of Progeria forward
- Be a valuable resource for families living with Progeria and their health caretakers

Together we *will* find the cure.

Leslie Gordon, MD, PhD
Medical Director, The Progeria Research Foundation, Inc.