

January 2008

Dear PRF Chapter Members,

Welcome! On behalf of The Progeria Research Foundation, Inc. (PRF), thank you for becoming part of our team. We are pleased to present this Guide for Chapters, to assist you in your activities to raise awareness about Progeria and help find the cure for this terminal disease.

Volunteer and staff leadership should be acquainted with the information contained herein; it is the official guide for state chapter operations.*

Now in its 9th year of profound growth (and consequently an increasing budget), the Board of Directors realized that, to accomplish the best results, PRF must become a part of local communities with the help of organized groups. To that end, state chapters have been established, under authority of the President, to assume responsibility for approved public awareness campaigns and fundraising events in a specific location. It is our belief that, with the formation and success of state chapters, PRF's goal of developing treatments and the cure for Progeria will be reached more rapidly, and thus more children's lives will be saved.

The Progeria Research Foundation's main office is committed to providing service, leadership and management support to state chapters. State chapters, in turn, must be committed to serving their communities with fidelity to PRF's mission and policies. The partnership formed by volunteers and staff in administering the state chapters is a vital one characterized by mutual respect and shared leadership. It is this unique type of alliance that has been the cornerstone of how PRF operates to advance its mission. In a spirit of mutual trust, respect, support and caring, we look forward to working with you toward the achievement of our ultimate goal: a cure for children with Progeria, so that they can live long and healthy lives.

Together, we *WILL* find the cure!

Audrey Gordon, Esq.
President, Executive Director

Scott D. Berns, MD, MPH
Chairman, Board of Directors

* We understand that individual chapters will need to exercise reasonable discretion and flexibility implementing policies in accordance with the unique circumstances of their chapter.

History, Accomplishments & Goals (January 2008)

The Progeria Research Foundation (PRF) was founded in March 1999 by the family, friends and colleagues of Sam, a Massachusetts child afflicted with Progeria. Progeria is a fatal, “premature aging” disease that afflicts children, who die of heart disease at an average age of 13 years.

MISSION: To discover the cure and effective treatment for Progeria and its aging related disorders.

VISION: To be the driving force worldwide to:

- Discover the cure
- Develop treatment
- Provide information and guidance
- Be a valuable resource for Progeria families

The governance of the corporation is vested in a national Board of Directors which serves without compensation and meets quarterly. There is also a volunteer Medical Director. Volunteer committees (public awareness, medical research, special events and fundraising committees) meet as needed. Staff includes a full-time Executive Director, a part-time Executive Assistant and a full-time Administrative Assistant/Clinical Trial Coordinator.

PRF has created and centralized all of the resources needed to propel forward as quickly as possible towards treatments and cure. Thanks to the steadfast support of thousands worldwide and the comprehensive research programs PRF has created, Progeria research has progressed at a pace virtually unheard of in the scientific community.

The results have been astounding. The following details PRF’s accomplishments:

- ✓ **Discovery of the Progeria Gene:** In 2003, PRF’s collaborative research team made history with the discovery of the Progeria gene. This discovery catapulted Progeria research into an age where treatments and a cure are closer than ever before. Not only has it led to further understanding of Progeria, but scientists now know that studying Progeria can help us learn more about heart disease and the normal aging process that affects us all.
- ✓ **The First-Ever Progeria Clinical Drug Trial:** In the four years since the gene discovery, PRF-funded researchers intensely studied this genetic defect, created mouse models and their work then supported a potential drug treatment for children with Progeria involving farnesyltransferase inhibitors, or FTI’s. PRF is now funding and co-coordinating this clinical drug trial, taking place at Children’s Hospital Boston.

The trial began on May 7, 2007 and is expected to last for 2 ½ years. Twenty-eight children from sixteen countries are participating, ages 3 to 15 years. Children come to Boston every four months, for testing and to receive new drug supply, and stay in Boston for 4-8 days each visit. To date PRF has raised \$1.5 million of the \$2 million needed to fund this trial.

- ✓ **The PRF Cell & Tissue Bank** is critical for research to occur. It provides medical researchers with genetic and biological material from Progeria patients and their families, so that research on Progeria and other aging-related diseases can be performed. In fact, the gene responsible for Progeria was identified using materials from the PRF Cell & Tissue Bank! Presently, PRF has an impressive 67 cell lines from affected children from all over the world and whose ages range from 8 months to 17 years, and 40 lines from their immediate relatives. With only 46 known children living with Progeria in the world today, we’ve been hard at work with the families and their physicians to gather these precious biological materials.

- ✓ **The PRF Medical & Research Database** is a collection of medical records of Progeria patients from all over the world. The data is rigorously analyzed to determine the best course of treatments to improve the children's quality of life, and to understand more about the basis of Progeria. To date, 3 healthcare recommendations for Cardiac Care, Nutrition and Occupational Therapy/Physical Therapy have been published to help children with Progeria in their daily lives. 70 children are enrolled in the program, and the critical, primary parameter for the Progeria clinical drug trial (weight) was identified using information contained in the Database.
- ✓ **Research Grants:** PRF's grants of up to \$100,000, for up to two years, have allowed innovative new research in Progeria to thrive. As of December 2007, PRF has funded 23 grants for Progeria-related research projects performed in 10 states and 3 countries - in just 8 years! In 2007, PRF funded a record 8 grants. Proposals are carefully evaluated by PRF's Medical Research Committee and Board of Directors. PRF solicits proposals worldwide and through its scientific workshops in a continuing effort to encourage researchers to work in this field.
- ✓ **Workshops on Progeria:** PRF has organized five scientific conferences that have brought together scientists and clinicians from all over the world, to share their expertise and cutting edge scientific data, and foster collaboration in the fight against this devastating, lethal disease. Many of the workshop attendees have said the programs PRF offers are essential to conducting Progeria-related work. In November 2007, PRF held its 5th conference, a 3-day meeting in Boston with 30 posters (double the number from the 2005 workshop) and 17 official speakers. Participant feedback was all 4's and 5's (highest rating is 5) in all areas. The clinical trial was clearly the main topic of interest to the 90 scientists and clinicians from 8 countries attending.
- ✓ **Publication of Scientific Papers:** A major goal of PRF is to promote awareness about the progress being made in the field of Progeria research. Interest has flourished since the gene discovery, as more and more high-level scientists produce data that will help to better understand Progeria and develop future treatments. Every year, the number of publications increases and 2007 is no exception; 27 scientific papers on Progeria, many of which acknowledge PRF grant, cell bank or database support, were published in 2007 in well-known, respected scientific journals read by thousands of researchers worldwide. In the past 5 years, 107 publications on Progeria have appeared. This is an average of 21.4 per year, a more than 10 fold increase in the number of publications from the previous 53 years!
- ✓ **Partnership with the National Institutes of Health (NIH):** PRF has brought Progeria to the forefront of research efforts, engaging large, reputable institutions such as NIH to invest their resources in Progeria. NIH has co-sponsored all five scientific meetings with PRF, and for the first time in NIH history, has provided funding for basic science research in this field.
- ✓ **Web Site/Public Awareness:** Before PRF was formed, virtually no one knew what Progeria was. Now, information about Progeria and our far-reaching message - that finding a cure may help millions with heart disease and other aging-related conditions - has reached people worldwide through PRF's web site, newsletters, educational materials and the media. ProgeriaResearch.org averages 15,000 visitors per month, and PRF's newsletters reach nearly 10,000 people in 49 countries.

Since the gene discovery, PRF's story has appeared on CNN, Primetime Live, Dateline, The Today Show, Discovery Channel, in Time magazine, People magazine, The New York Times, and dozens of other media outlets with a keen interest in Progeria and PRF's work. In January 2007, PRF and the Progeria Clinical Drug Trial were featured on the front page of The Wall Street Journal, (enclosed). With an audience of 2.1 million, the trial and PRF's tremendous progress received additional exposure worldwide. With this vast expansion of outreach, more children are being diagnosed and helped than ever before.

- ✓ **Volunteer Expansion:** Thousands have joined PRF's quest for a cure in many ways, from organizing fundraisers, to translating for non-English speaking families, to stuffing envelopes! These "Miracle Makers" selflessly give their time and talents to raise money and awareness. Since October 2005, PRF has expanded its volunteer base to include four chapters. In May 2007, PRF initiated an Ambassador Program, wherein volunteers pick up the families participating in the clinical drug trial from the airport and get them settled in. PRF has also amassed a team of 30 translators to help trial families that do not speak English.

- ✓ **Progeria Family Outreach-The PRF Progeria Family Message Board and Chat Room:** In keeping with our mission of continuing to provide valuable resources for families of children with Progeria, PRF has created a private message board web site for them. This on-line tool helps them get to know each other, and develop a support network of people with whom they can share concerns and ideas on how best to care for their children. Parents can also ask questions and receive answers to medical issues from Dr. Leslie Gordon, PRF's Medical Director, and are encouraged to discuss medical issues amongst themselves. The message board is free and confidential, and families are excited about this new (launched in June 2005) vehicle for increased communication amongst their many families around the world.

- ✓ **Increased Resources for PRF Programs:** Virtually every year, PRF has enjoyed a much-needed increase in revenue. In 2007, 89% of the money spent was devoted to programs (see expense analysis, attached). In 2007, a record eight grants have been funded and program expenses have increased as more children are tested and participate in our Cell & Tissue Bank and Medical & Research Database. With a 2005 budget of \$718,000, in June 2006 PRF took a giant leap forward by committing to a \$2 million clinical trial – in addition to all other, pre-existing expenses - and is meeting that challenge thanks to our ever-growing support system.

PRF IN THE FUTURE: PRF WILL CONTINUE WORKING TO FIND THE CURE BY:

- Completing the first-ever Progeria clinical drug trial, with the hope that FTIs will prove an effective treatment and the trial results will pave the way for other research and clinical trial directions.

- Keeping the Diagnostic Testing Program up and running continually, so that early and accurate diagnoses can be made and medical intervention can be implemented.

- Increasing the number of participants in the Cell & Tissue Bank and Medical & Research Database projects, and keeping those vital projects operating so that scientists can use them as research tools to understand Progeria, heart disease and cellular aging.

- Funding additional research proposals that focus on studying the Progeria gene and how this defect can be corrected.

- Holding additional scientific meetings to continue to expand the collaborations and novel ideas for treatments and a cure.

- Maintaining and fostering our partnership with the National Institutes of Health to encourage more funding of Progeria research and continued workshop support.

- Increasing public awareness so more children will be properly diagnosed at earlier ages, more scientists will get involved in our efforts, and more individuals will support our cause.

- Expanding our volunteer and revenue sources to reach the \$2 million needed for the clinical drug trial, and support PRF's other programs.
- Moving even closer to our mission of finding treatments and the cure for Progeria!

CONCLUSION

Before PRF was formed, there was no place for these children to go for medical help, no place for parents or doctors to turn for information, no source of funding for researchers who wanted to do Progeria research. If these children were to be helped at all, they would have to be taken out of the background where they had been essentially forgotten, and put in the forefront of scientific research. They now are, thanks to PRF's vision, commitment and leadership.

PRF has addressed all the critical areas to propel the research forward, and we look, with you, to the future of developing treatments and a cure with excitement and optimism. And as awareness of Progeria, its link to heart disease and aging, and the programs now available for research spreads throughout the world, we move closer to saving the lives of these special children.

PRF's remarkable accomplishments are due in large part to grants from organizations like yours. Your generosity has allowed PRF to become the driving force in Progeria research and education. We thank you, and look forward to our continued work together to find the cure for these special children.

STATE CHAPTER GUIDELINES

1. GENERAL OVERVIEW

Each chapter shares The Progeria Research Foundation's mission and purpose, and is committed to furthering that mission by conducting and assisting in fund-raising and public awareness activities on PRF's behalf.

These chapter guidelines may be altered, amended, modified or added to from time to time, by the President of PRF and forwarded to all state chapters, specifying the effective date.

Individual chapters will need to exercise reasonable discretion and flexibility implementing policies in accordance with the unique circumstances of their chapter.

2. OBLIGATIONS AND LIABILITY

State chapters are required to comply with and observe all laws, ordinances, and rules and regulations of the United States, of the state and any subdivision thereof wherein the territory of the state chapter is located, and of all federal, state and local regulatory bodies having jurisdiction over said territory.

It is PRF policy to protect state chapter officers, board members and committee members from civil liability arising from any acts or omissions related to the performance of their duties, if such persons acted in good faith for a purpose that they reasonably believed to be in the best interests of the state chapter or PRF. For this purpose, PRF maintains director's and officer's liability coverage under a not-for-profit organization insurance policy.

3. ADDRESSES

National Office Address

The official address of The Progeria Research Foundation, its staff, officers and directors is:
PO Box 3453

Peabody, MA 01961-3453

Delivery address: 532 Lowell Street, 2nd Floor, Peabody, MA 01960

Anyone with notices, correspondence or documents to be given to or filed with PRF, its staff, officers or directors shall direct them to this address unless notified in writing by the President of PRF.

Chapter Address

The official address of a state chapter shall be provided to the national office of PRF.

4. ORGANIZATION, ADMINISTRATION AND STRUCTURE

Bylaws of State Chapters

The standard form of state chapter bylaws (attached) is designed to meet the needs of all state chapters.

PRF Logo, Pictures of Children

Chapters shall use the PRF logo on all printing and graphics prepared by or for chapters for local distribution for whatever purpose, including fund raising and education. Use of pictures of children with Progeria shall be determined on a case-by-case basis after discussion between the chapter leaders and the President.

Certificate of Organization

A state chapter's Certificate of Organization is its "charter," which empowers it to further PRF's goals within its territory.

If, in the opinion of the President of PRF, a state chapter is in deliberate and persistent violation of any standard or policy of PRF, including those in the state chapter bylaws and this manual, or if a state chapter has become inactive, the certificate of recognition may be withdrawn through written notification from the President to any officer of the state chapter in question, setting forth the reasons for withdrawal.

Whenever the Certificate of Organization of a state chapter is surrendered or withdrawn, all of its assets and property, including its bank accounts, files, equipment, and records shall be relinquished to PRF or to a representative designated by the President.

Membership

Membership in a state chapter shall consist of all volunteers. Committed, active and effective state chapter volunteers are necessary if a state chapter is to develop and implement successful activities. State chapter membership is open to anyone interested in helping advance PRF's mission, without regard to race, ethnic identity, national origin, religion, age, mental or physical disability, gender, and sexual orientation or preference or marital status. There is no limit to the number of volunteers a state chapter may have.

Nature of Activities

It is the function of every state chapter to engage in education programs and to conduct fund-raising events and/or campaigns. Financing of scientific research necessitates national coordination of resources, review procedures and criteria and, consequently, is within the exclusive purview of the national office of PRF. The state chapters may neither engage in scientific research, nor give financial support to the research projects of others, except at the specific request and/or authorization of the President.

Appointments

The business and affairs of the state chapter are managed and controlled by a state chapter Board of Directors, including the state chapter's officers and appointed chairs of committees, if any (for a particular special event, for example). Volunteers can hold more than one position.

Standards of Behavior

PRF expects volunteers and staff to act responsibly at all times and to be competent to perform their duties. Staff who have direct responsibility in the conduct of an event or function, or when assisting in the management of an event or function, are not permitted to consume alcoholic beverages when performing their duties.

Records, Financial Reporting, Expenditures

State chapters must maintain efficient and complete records of their activities. This will ensure adequate reports to state chapter members, their communities and to PRF.

The fiscal year of PRF and of all its state chapters is the calendar year, ending on December 31. The reports are the regular financial accounting reports, to be filed annually by the end of January, and special events reports, to be provided within 45 days following an event.

State chapters are responsible for keeping accurate and timely records of contributions they receive, and for either providing or working with the PRF national office to provide documentation to donors as required by the IRS to substantiate deductibility.

All assets held or received by any state chapter belong to PRF, and are to be expended or used

subject to its certificate of incorporation and the governance of the national Board of Directors.

State chapters may maintain one checking account to serve as the operating account from which checks can be drawn locally. Two signatories are required of checks drawn on the operating account.

Monthly bank statements must be reviewed and initialed monthly by the state chapter Executive Director, and reviewed periodically, but no less than every 4 months, by the state chapter Treasurer.

Funds of PRF are public funds held in trust and are to be protected and administered with the utmost care and stewardship. State chapter volunteers and staff must ensure that there is not a conflict of interest in their dealings in fiscal or other matters involving their state chapter, any other state chapter or the national office.

A state chapter is not permitted to borrow funds from outside sources nor to loan funds to employees or others.

State chapters may not expend funds for the purchase, erection or maintenance of buildings (other than for the maintenance of leased premises), monuments or similar building projects.

PRF, as part of its corporate fiduciary responsibility, may examine or audit at any time, any and all records and books of any state chapter. State chapters are expected to furnish promptly to PRF any financial or other information with respect to their activities that PRF may reasonably request.

STANDARD FORM OF STATE CHAPTER BYLAWS

ARTICLE I Names and Offices

Section 1. *Name.* This state chapter shall be known as the _____ Chapter of The Progeria Research Foundation, Inc. (hereinafter PRF).

Section 2. *Offices.* The central and principle office of the state chapter shall be in the city (town) of _____, county of _____, state of _____
The state chapter may also have offices at such other places as the state chapter Board of Directors may from time to time designate.

ARTICLE II Purpose

The purpose of the state chapter shall be to carry out the mission and strategic plan of PRF, as determined by the national Board of Directors, in accordance with the Certificate of Incorporation of PRF and in conformity with its chapter guidelines, recommendations and policies as PRF may from time to time prescribe.

ARTICLE III State Chapter Board of Directors

1. *Number.* The business and affairs of the state chapter shall be managed by the state chapter Board whose members must be volunteers serving without salary or compensation. The state chapter Board shall consist of the Chair, Vice Chair, Secretary and Treasurer, and such other members as they deem appropriate up to 15. Volunteers can hold more than one position within the state chapter.

2. *Election.* The officers, members and committee chairs of the state chapter Board shall be elected every 2 years, for a term of two (2) years and shall serve for such term until the election and qualification of their respective successors. The state chapter Board shall decide if there should be a maximum number of terms for which their Board members shall serve, and if so, shall put such term limits in writing herein:

3. *Regular Meetings.* State chapter Board of Directors shall meet quarterly or as deemed appropriate by the state chapter officers. Minutes must be taken at all meetings and kept on record at the state chapter office. There shall be a volunteer training and orientation meeting at such intervals as the officers deem necessary, the first such meeting to be attended and assisted by PRF's President. These meetings may incorporate content and presentations provided by PRF's national office.

4. *Special Meetings.* Special meetings of the state chapter Board may be called by the Chair or, in the event of unavailability or illness, the Vice Chair, and by request of one-third of the members of the state chapter Board or by the national office.

Any and all business may be transacted at any state chapter Board meeting. Board members not able to attend in person may participate in a meeting of the state chapter Board by telephone conference or similar communications equipment allowing all persons participating in the meeting to hear each other at the same time.

5. *Chair.* At all meetings of the state chapter Board, the Chair of the state chapter, or in his/her absence, the Vice Chair of the state chapter, or in the absence of both the Chair and Vice Chair, a board member chosen by the members present shall preside.

6. *Quorum.* At all meetings of the state chapter Board, one-third of the members shall be necessary and sufficient to constitute a quorum for the transaction of business, and the act of a majority of the members present at any meeting at which there is a quorum shall be the act of the state chapter Board.

7. *Vacancies.* Any vacancy in the state chapter Board may be filled by the vote of a majority of the remaining members.

8. *Powers.* All the state chapter's powers, except as otherwise provided for in these bylaws, shall be vested in, and shall be exercised by the state chapter Board, subject to the Chapters guidelines, recommendations and policies prescribed by PRF. In addition, the state chapter Board shall have the power to remove any officer, committee Chair or member, whenever in its judgment the best interests of the state chapter will be served thereby.

9. *Parliamentary Authority.* The conduct of business at all meetings of the state chapter Board shall be governed by Robert's Rules of Order.

ARTICLE IV Officers

1. *Number.* The officers of the state chapter Board of Directors shall be a Chair, one or more Vice Chairs, a Secretary, a Treasurer, and such other officers with such powers and duties not inconsistent with these bylaws as from time to time may be proposed by the state chapter Board.

2. *Vacancies.* If any office of the state chapter becomes vacant, the state chapter Board shall elect by majority vote an officer to fill such vacancy. Within ten (10) days thereafter the Secretary shall notify PRF of the name and address of the officer so elected. The state chapter Vice Chair may fill any office that is vacant until that position is filled.

3. *The Chair.* The Chair shall preside at all meetings of the state chapter Board of Directors and shall appoint all committee chairs with the advice and consent of the Board. The Chair may, as authorized by the state chapter Board, sign and execute all authorized checks or other obligations in the name of and on behalf of the state chapter. The Chair shall have general charge and supervision of the affairs of the state chapter and shall perform such other duties as may be assigned from time to time by the state chapter Board. The Chair shall maintain close liaison with PRF's President on behalf of the state chapter Board.

4. *The Vice Chair.* At the request of the Chair, or in the event of the Chair's absence or disability, the Vice Chair may perform any and all the duties of the Chair and shall have such other powers and perform such other duties as the state chapter Board may from time to time assign. In case of multiple Vice Chairs, the seniority or ranking shall be indicated by numerical designation. The Vice Chair may fill any state chapter office position or any state chapter Board vacancy until those positions are filled.

5. *The Secretary.* The Secretary shall attend meetings and keep the minutes of all meetings of the state chapter Board of Directors. The Secretary shall be responsible for the giving and serving of all notices of the state chapter. The Secretary shall, in general, perform or cause to be performed all the duties incident to the office of Secretary, subject to the direction of the state chapter Board, and such other duties as may be assigned from time to time by the state chapter Board.

6. *The Treasurer.* The Treasurer shall, subject to the direction of the chapter Board, have general charge of the financial affairs of the chapter and shall cause to be entered regularly on the books full and accurate account of all monies and property received and all monies and obligations paid or incurred by the state chapter. The Treasurer shall exhibit such books at all reasonable times to any member of the state chapter Board and to any accredited representative of PRF.

The Treasurer shall be designated as one of the co-signers of checks on the state chapter operating account, and shall periodically review the bank reconciliation statements of state chapter bank accounts.

7. *State Chapter Counsel.* Where practical, the Chair of the state chapter shall appoint a volunteer attorney as legal advisor to counsel and assist the state chapter Board of Directors and the officers in conducting their affairs. Such appointee serves as a member of the state chapter Board.

8. *Other Committees.* Other committees may be formed to accomplish the purposes and programs of PRF, such as special events committees for particular events, and youth development committees. Committee Chairs shall be appointed by the state chapter Chair with the advice and consent of the state chapter Board.

ARTICLE V Contracts

Unless authorized by PRF and by the state chapter Board, no officer, agent or member of the state chapter shall have any power or authority to bind the state chapter or PRF by any contract or engagement or to pledge its credit or render it liable financially for any purpose or to any amount. Once properly authorized, the state chapter Chair is the appropriate signatory on such agreements.

ARTICLE VI Fiscal Year

The fiscal year of the state chapter shall begin on January 1 and end on December 31.

ARTICLE VII Records, Financial Reporting, Expenditures

Regular financial accounting reports are to be submitted to PRF annually by the end of January, and special events reports within 45 days following an event. As part of its corporate fiduciary responsibility, PRF may examine or audit from time to time, any and all records and books of any state chapter.

ARTICLE VIII Liability

The officers and state chapter Board of Directors of any state chapter shall, individually and collectively, be free from civil liability arising from any acts or omissions related to the performance of their duties if such persons acted in good faith for a purpose which they reasonably believed to be in the best interests of the state chapter or PRF.

ARTICLE IX Amendments, Supplementary Rules

These bylaws may be amended only by PRF. supplementary rules not inconsistent with these bylaws, however, may be adopted by a majority vote at any regular or special meeting of the state chapter Board of Directors.

The following supplementary rules are hereby incorporated to facilitate the administration of the _____ State Chapter of The Progeria Research Foundation: