



The Progeria Research Foundation

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Dear PRF International Partner,

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

Your group's leadership should be acquainted with the information contained herein; it is the official guide for International Partner operations.*

Now entering its 10th year of profound growth (and consequently an increasing budget), the PRF Board of Directors realized that, to accomplish the best results, PRF must become part of local communities around the world, with the help of organized groups. To that end, Chapters in the United States and International Partners outside of the US have been established 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 Chapters and International Partnerships, 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 its International Partners. International Partners, in turn, must be committed to serving their communities with fidelity to PRF's mission and policies. The affiliation formed between US-based volunteers and staff and the International Partners 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 partners will need to exercise reasonable discretion and flexibility implementing policies in accordance with the unique circumstances of their country and group.



History, Accomplishments & Goals (October 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 development 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 following 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 \$1.67 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 48 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. 71 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 on Progeria increases, many of which acknowledge PRF grant, cell bank or database support. These articles appear in respected scientific journals read by thousands of researchers worldwide. The average number of scientific publications on Progeria since 2002 is more than 10 times that of the previous 50 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. 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 seven chapters, and in 2008 international partnerships are beginning to be established.
- ✓ **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 and a record eight grants were funded. Program expenses increase as more children are tested and more researchers become involved. 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 1st-ever Progeria clinical drug trial, with the hope that FTIs are an effective treatment and the trial results will pave the way for other research and 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 projects 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.

INTERNATIONAL PARTNERS GUIDELINES

1. GENERAL OVERVIEW

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

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

Individual International Partners will need to exercise reasonable discretion and flexibility implementing policies in accordance with the unique circumstances of their country and group.

2. OBLIGATIONS AND LIABILITY

International Partners are required to comply with and observe all laws, ordinances, and rules and regulations of their respective country, of the territory and any subdivision thereof wherein the the group is located, and of all regulatory bodies having jurisdiction over said territory.

Because International Partners are, by their very definition, outside of the United States, PRF cannot protect International Partner members from civil liability arising from any acts or omissions related to the performance of their duties, even if such persons acted in good faith for a purpose that they reasonably believed to be in the best interests of the group or PRF.

3. ADDRESSES

United States 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 PRF's President.

International Partner Address

The official address of an International Partner shall be provided to the US office of PRF.

4. ORGANIZATION, ADMINISTRATION AND STRUCTURE

Bylaws of International Partners

The standard form of International Partner bylaws (attached) is designed to meet the needs of all International Partners.

PRF Logo, Pictures of Children

International Partners shall use the PRF logo on all printing and graphics prepared by or for International Partners for local distribution for fundraising and education purposes. Use of pictures of children with Progeria and accompanying text shall be determined on a case-by-case basis after discussion between the International Partner leaders and the President.

Authorization of Organization

Acceptance by PRF's United States office authorizes an International Partner to further PRF's goals within its territory. If, in the opinion of the President of PRF, an International Partner is in deliberate and persistent violation of any standard or policy of PRF, including those in this guide,

or if an International Partner has become inactive, this acceptance may be withdrawn through written notification from the President to any leader of the International Partner in question, setting forth the reasons for withdrawal.

Whenever the authorization of an International Partner 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 of an International Partner shall consist of all volunteers. Committed, active and effective volunteers are necessary if an International Partner is to develop and implement successful activities. 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 an International Partner may have.

Nature of Activities

It is the function of every International Partner to engage in education programs and to conduct fundraising events and/or campaigns. Financing of scientific research necessitates coordination of resources, review procedures and criteria and, consequently, is within the exclusive purview of PRF. International Partners 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 International Partners are managed and controlled by a Board of Directors, including the 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 to act responsibly at all times and to be competent to perform their duties. Those who have direct responsibility in the management of an event or function are not permitted to consume alcoholic beverages when performing their duties.

Records, Financial Reporting, Expenditures

International Partners must maintain efficient and complete records of their activities. The fiscal year of PRF and of all its International Partners is the calendar year, ending December 31. Financial accounting reports must be filed annually by the end of January, and special events reports must be provided within 45 days following an event.

International Partners 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 acknowledgement letters and/or documentation to donors to substantiate deductibility, if applicable.

All assets held or received by any International Partner belong to PRF, and are to be expended or used subject to PRF's certificate of incorporation and governance of PRF's Board of Directors.

International Partners 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 no less than every 4 months by the Treasurer.

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

An International Partner may not borrow funds from outside sources nor loan funds to others.

International Partners may not expend funds for the purchase, erection or maintenance of buildings, 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 International Partner. International Partners 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 INTERNATIONAL PARTNER BYLAWS

ARTICLE I Names and Offices

1. *Name.* This International Partner shall be known as the (suggested inclusion: name fo country) _____ Partner of The Progeria Research Foundation, Inc. (PRF).
2. *Offices.* The central and principle office of the International Partner shall be in the city/town/province of _____, country _____. The International Partner may also have offices at such other places as its Board of Directors may from time to time designate.

ARTICLE II Purpose

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

ARTICLE III International Partner Board of Directors

1. *Number.* The business and affairs of the International Partner shall be managed by the International Partner Board whose members must be volunteers serving without salary or compensation. The International Partner 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 group.
2. *Election.* The officers, members and committee chairs of the International Partner 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 International Partner 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.* International Partner Board of Directors shall meet quarterly or as deemed appropriate by them. Minutes must be taken and kept on record at the International Partner office. There shall be a volunteer orientation meeting at such intervals as the officers deem necessary. These meetings may incorporate content and presentations provided by PRF's national office.
4. *Special Meetings.* Special meetings of the International Partner 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 International Partner Board or by the PRF office.

Any and all business may be transacted at any International Partner Board meeting. Board members not able to attend in person may participate in a meeting of the International Partner 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 International Partner Board, the Chair of the International Partner, or in his/her absence, the Vice Chair of the International Partner, 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 International Partner 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 shall be the act of the International Partner Board.

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

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

ARTICLE IV Officers

1. *Number.* The officers of the International Partner 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 International Partner Board.

2. *The Chair.* The Chair may, as authorized by the International Partner Board, sign and execute all authorized checks or other obligations in the name of and on behalf of the International Partner. The Chair shall have general charge and supervision of the affairs of the International Partner and shall perform such other duties as may be assigned from time to time by the International Partner Board. The Chair shall maintain close liaison with PRF's President on behalf of the International Partner Board.

3. *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 International Partner Board may from time to time assign. The Vice Chair may fill any International Partner office position or any International Partner Board vacancy until those positions are filled.

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

5. *The Treasurer.* The Treasurer shall have general charge of the financial affairs of the International Partner 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 International Partner. The Treasurer shall exhibit such books at all reasonable times to any member of the International Partner Board and to PRF's President.

The Treasurer shall be designated as one of the co-signers of checks on the International Partner operating account.

6. *International Partner Counsel.* Where practical, a volunteer attorney shall be appointed as legal advisor to counsel and assist the International Partner Board of Directors in conducting their affairs. Such appointee is a member of the International Partner Board.

7. *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.

ARTICLE V Contracts

Unless authorized by PRF and by the International Partner Board, no officer, agent or member of the International Partner shall have any power or authority to bind the International Partner 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 International Partner Chair is the appropriate signatory on such agreements.

ARTICLE VI Fiscal Year

The fiscal year of the International Partner 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 International Partner.

ARTICLE VIII Liability

PRF cannot protect International Partner members from civil liability arising from any acts or omissions related to the performance of their duties, even if such persons acted in good faith for a purpose that they reasonably believed to be in the best interests of the group 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 International Partner Board of Directors.