AUTHORIZATION FOR DISCLOSURE OF HEALTH INFORMATION

I authorize: **Any and all providers**

(NAME OF PROVIDER OR ORGANIZATION)

to disclose the following information from the health records of:

Current Name: _____

LAST FIRST MIDDLE MAIDEN

Birth Date: _____

MONTH DATE YEAR

Dates of Medical Care: _____

To be disclosed to:

Akiko Shimamura, MD, PhD
Boston Children's Hospital
Karp Family Research Laboratory, 8210
Boston, MA 02115
Phone: 617-919-6109
Fax: 617-730-4734

or

Kasiani Myers, MD
Cincinnati Children's Hospital
240 Albert Sabin Way, T12 476AE
Cincinnati, Ohio, 45229
C/O Sara Loveless RN, Research Nurse SDSR
Phone: 513-803-7656
Fax: 513-636-6927

Protected Health Information ("PHI") to be disclosed:

- ✓ Names and addresses of physicians following patient
- ✓ Hospital admission and discharge summaries
- ✓ Pulmonary function studies
- ✓ Growth charts
- ✓ Pathology reports
- ✓ Laboratory results
- ✓ Imaging study reports
- ✓ Consultation letters
- ✓ Medication records
- ✓ Clinic notes, Flow sheets
- ✓ Other (Specify):_____

Purpose: The purpose of this disclosure is to provide follow up information about diagnosis and treatment for Shwachman-Diamond Syndrome as part of the research program of the North American Shwachman Diamond Syndrome Registry. This research program is focused primarily on collecting medical and non-medical information and opinions from people suspected of having SDS, to better learn how this syndrome behaves and how it affects different people and families. Since this syndrome is rare, multiple institutions are combining efforts to learn the most about SDS as possible.

I understand that this authorization for disclosure of my PHI, unless expressly limited by me in writing, will extend to all aspects of diagnosis and treatment as listed above and may include testing and/or treatment for fertility.

I understand that my PHI will be used for research purposes as described above. Redisclosure: I understand the researchers may need to disclose my PHI to institutional review boards and other entities and individuals as required by law. I understand that once my PHI has been disclosed to the researchers, the privacy rules in a federal law called the Health Insurance Portability and Accountability Act ("HIPAA") may no longer apply. However, I understand that confidentiality protections under federal and state law will apply to the research use of this information.

I understand that I do not have to sign this authorization. I understand that this authorization may be revoked in writing at any time by writing to the Long-Term Follow-Up Program listed above. If I do revoke my authorization, I understand that PHI that has already been released may still be used by the researchers. The facility, its employees, officers and physicians are hereby released from any legal responsibility or liability for disclosure of the above information to the extent indicated and authorized herein.

Printed Name: _____

Signed: _____ **Date: _____**

(Patient, Parent, or Next-of-Kin)