

## ORGANIZATIONAL GUIDE FOR SDS PATIENT CARE

With a diagnosis of Shwachman Diamond Syndrome, there are several important documents and records that should be organized to keep track of a patient's care. A well-organized system for storing and filing these documents, whether hard-copy or electronic, is important for the long-term care of the patient.

### A binder for organizing patient care

SDSF suggests creating a binder (or an electronic system) to manage your SDS care. In this binder, important medical paperwork should be included such as the patient information sheet, medical team contact information, a log of appointments, a list of medications, a monthly calendar to mark appointments/therapy sessions, a log of lab results, bone marrow biopsy procedures, x-rays and CT scans, and any other pertinent information to meet your specific needs. We recommend purchasing a heavy 3-ring binder and tabs/folders to organize your binder.

We have provided some forms that you can print out to get you started in creating your own care binder.

- **Binder Cover Sheet**
  - Slide this sheet in the front of your binder
- **Patient Information Sheet**
  - Fill out this form to provide information about the SDS patient.
- **Medical Team Contact Information**
  - In this section you can also include business cards, emergency room instructions, etc.
- **Calendar**
  - On this form, fill out a monthly calendar to include appointments, therapy sessions, reminders of when to administer medications, lab draws, etc.
- **Appointment Log**
  - In this section you can also include doctor notes, a list of questions asked/answers received, or other reports received from your appointments.
- **Medication List**
  - In this section you can also include other pharmacy and prescription information.
- **Lab Results**
  - **CBC Results**
  - In this section, you can include copies of all CBCs and other lab results (vitamin levels, liver enzymes, bone marrow biopsy results, etc.)
- **Growth**
  - **Weight & Height Log**
  - In this section, you can also include feeding schedules, information from nutritionists, high-calorie recipes, supplement information, growth hormone information, etc.

- Bone Marrow Biopsies
  - **BMB Log**
  - In this section, log the dates and information regarding bone marrow biopsy procedures. Also, attach any reports if available.
- **Transfusion Log**
  - In this section, log pertinent information relating to transfusions that the SDS patient needs. Also, attach any reports if available.
- **X-Rays & CT scans**
  - In this section, you can log all x-rays and CT scans, as well as include any reports if available.
- Other
  - Organize your binder to meet the specific needs of the SDS patient.

## Electronic tools to help organize patient care

Since technology has allowed us to go paperless in many ways, it may be your personal preference to keep a “digital binder” or to utilize a different digital system to organize your SDS care. The following is a list of suggestions on how to utilize a digital organizational system.

- MyChart (iOS app) (Android)
  - Gives patients (or caregivers of minors) access to a secure, convenient and free way to manage their personal health care information at participating hospitals. Check with your doctor if a patient portal similar to MyChart is available and for the instructions to get set up.
- FollowMyHealth (iOS app) (Android)
  - Gives patients (or caregivers of minors) access to a secure, convenient and free way to manage their personal health care information at participating hospitals. Check with your doctor if a patient portal similar to FollowMyHealth is available and for the instructions to get set up.
- Microsoft HealthVault
  - Microsoft HealthVault helps you gather, store, use, and share health information for you and your family. You can keep all of your health records in one place that’s organized and available to you online.
- Evernote (iOS app) (Android)
  - This app is great for keeping notes about doctor appointments, keep a list of questions for an upcoming appointment, scan in paper copies of CBC results, doctor’s notes, etc.
- Microsoft Excel spreadsheet
  - The binder guide above is available electronically within a Microsoft Excel spreadsheet in which each section of the binder is located in the tabs of the spreadsheet. **Download the spreadsheet “SDS Patient Care Spreadsheet” located on the SDSF website under Family Support.**

# Care Binder for

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## Patient Information Sheet

Patient Info			
Patient Name:		Blood Type:	
Address:			
Address 2:			
City, State, Zip:			
Phone:		Email:	
Emergency Contact Name:		Emergency Contact Phone:	
Primary Insurance:		Primary Ins. Policy #:	
Secondary Insurance:		Secondary Ins. Policy #:	

List of Diagnoses/Conditions		
Date	Diagnosis	Explanation

Patient Allergies		
Date	Allergy	Symptoms & Treatment if Exposed

Additional Patient Information

## SDS Medical Team Contact Info

Primary Care Provider			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; text-align: center;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

Hematologist			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; text-align: center;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

Gastroenterology			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; text-align: center;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

## SDS Medical Team Contact Info

Endocrinology	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	

Dental / Oral Surgery	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	

Allergy / Immunology	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	

## SDS Medical Team Contact Info

Cardiology			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

Neurology			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

Nutrition			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 70%;"></td> <td style="width: 30%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

## SDS Medical Team Contact Info

Therapy	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	

Therapy	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	

Other:	
Doctor Name:	
Address:	
Address 2:	
City, State, Zip:	
Phone:	Fax:
Email:	
Nurse Contact Info:	
Notes:	



## SDS Medical Team Contact Info

Other: _____			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;"></td> <td style="width: 40%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			

Other: _____			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;"></td> <td style="width: 40%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
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Email:			
Nurse Contact Info:			
Notes:			

Other: _____			
Doctor Name:			
Address:			
Address 2:			
City, State, Zip:			
Phone:	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 60%;"></td> <td style="width: 40%; padding: 2px;">Fax:</td> </tr> </table>		Fax:
	Fax:		
Email:			
Nurse Contact Info:			
Notes:			



## Appointment Log

Patient Info	
Patient Name:	
Date of Birth:	

Doctor Appointments, Hosptial Visits, Therapy Sessions, etc.			
Date	Specialty/Doctor	Reason for Visit	Notes/Outcome/Next Appt

## Current Medications

Date		Medication Name	Reason Prescribed	Prescribing Dr	Pharmacy that Fills
Start	Stop				
Dose/Frequency			Notes/Instructions		

Date		Medication Name	Reason Prescribed	Prescribing Dr	Pharmacy that Fills
Start	Stop				
Dose/Frequency			Notes/Instructions		

Date		Medication Name	Reason Prescribed	Prescribing Dr	Pharmacy that Fills
Start	Stop				
Dose/Frequency			Notes/Instructions		

Date		Medication Name	Reason Prescribed	Prescribing Dr	Pharmacy that Fills
Start	Stop				
Dose/Frequency			Notes/Instructions		





## Log of Bone Marrow Biopsy Procedures

Patient Info	
Patient Name:	
Date of Birth:	

Log of Bone Marrow Procedures		
Date	Doctor	Notes about the Procedure
BMB/Aspirate Results (Attach reports, if available)		

Date	Doctor	Notes about the Procedure
BMB/Aspirate Results (Attach reports, if available)		

Date	Doctor	Notes about the Procedure
BMB/Aspirate Results (Attach reports, if available)		

Date	Doctor	Notes about the Procedure
BMB/Aspirate Results (Attach reports, if available)		

## Log of Bone Marrow Biopsy Procedures

Date	Doctor	Notes about the Procedure
<b>BMB/Aspirate Results (Attach reports, if available)</b>		

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Date	Doctor	Notes about the Procedure
<b>BMB/Aspirate Results (Attach reports, if available)</b>		

Date	Doctor	Notes about the Procedure
<b>BMB/Aspirate Results (Attach reports, if available)</b>		





## Log of X-Rays & CT Scans

Patient Info	
Patient Name:	
Date of Birth:	

X-Rays and CT Scans			
Date	Specialty/Doctor	Reason for X-Ray/CT Scan	Results/Explanation (Attach reports)