"Reaching for a Cure"
LGDA
Lymphangiomatosis & Gorham's Disease Alliance

Patient Information Form

Lymphangiomatosis & Gorham's Disease Alliance
19919 Villa Lante Place Boca Raton, FL 33434
Phone: (561) 441-9766 www.LGDAlliance.org

PATIENT INFORMATION

Date | What is the patient's diagnosis? | Age at diagnosis

Last Name | First Name | Middle Name | Male / Female | Date of Birth

Address | City | State | Zip Code

Country | Telephone | Email

What areas of the patient's body are affected? Check all that apply:

- ☐ Heart ☐ Liver ☐ Intestines ☐ Thoracic Duct ☐ Spine ☐ Shoulder ☐ Leg(s)
- ☐ Lungs ☐ Spleen ☐ Gallbladder ☐ Aorta ☐ Pelvis ☐ Jaw ☐ Hands
- ☐ Head ☐ Kidney ☐ Esophagus ☐ Skin ☐ Ribs ☐ Arm(s) ☐ Feet

What symptoms has the patient experienced? Check all that apply:

- ☐ Bone Pain ☐ Fracture ☐ Abdominal Pain ☐ Nausea ☐ Vomiting ☐ Diarrhea ☐ Abdominal Distention
- ☐ Headache ☐ Swelling ☐ Slow Growth ☐ Fever ☐ Rash ☐ Cough ☐ Wheezing
- ☐ Chest Pain ☐ Trouble Beathing ☐ Fluid around lungs ☐ Fluid around heart ☐ Malnourishment ☐ Frequent Infection ☐ Other

What was the first symptom(s) experienced?

How long did the Patient experience symptoms before diagnosed? | How many doctors did the patient see before being diagnosed?

What tests has the patient had? Check all that apply.

- ☐ X-ray ☐ CT Scan ☐ MRI ☐ Biopsy ☐ Bone Scan ☐ Lymphangiogram ☐ DNA Testing

What medications/treatments has the patient had? Check all that apply

- ☐ Interferon ☐ pamidronate ☐ Vincristin ☐ shunt ☐ sclerotherapy ☐ bone surgery ☐ other surgery
- ☐ Thalidomide ☐ sirolimus ☐ octreotide ☐ drain ☐ pleurodesis ☐ radiation

Is the Patient disabled due to his/her diagnosis ? | If yes, in what way is he/she disabled?

Please list any other diagnoses the Patient has:

WHO IS PATIENT'S MAIN DOCTOR FOR LYMPHANGIOMATOSIS or GORHAM'S DISEASE?

Name | Hospital | Specialty

Address | City | State | Zip

Country | Telephone | Email

How far do you travel to see this doctor? | How frequently do you see this doctor? | Are you satisfied with your care?

Name of Person Completing this form | Relationship to Patient

Address of Person Completing Form | City | State | Zip

Country | Telephone | Email

As part of our patient support program LGDA tries to match interested patients and families who share common experiences, live in the same regions, and/or receive medical care from the same physicians and facilities. The program is strictly voluntary and you may opt in or out at any time by sending an email to our Director of Patient Support at support@LGDAlliance.org.

Do you wish to participate in LGDA's patient matching program? | If yes, how would you like to be contacted?

The purpose of this form is to compile a database of known patients and gather some basic information regarding their experiences with lymphangiomatosis and Gorham's disease. This information will help LGDA in its mission to provide support to the patient community and bring awareness of these conditions to research professionals and funding sources throughout the world. The information obtained through this form will also be used to guide the structure of a formal Patient Registry for lymphangiomatosis and Gorham's disease. The LGDA will not release the name or contact information of the patient or the person completing the form without the written consent of said person (or his/her legal guardian, if a minor). Return of this completed form constitutes understanding of its purpose and use by the LGD Alliance and its professional partners.

Thank you for completing this form. It will help the LGDA to improve patient support and research initiatives. Please click on the "Submit" button in the top right of the form to submit completed form. You may click the Print button to print a copy for your records. Again, we thank you for your participation.

Print Form