



LOEYS-DIETZ SYNDROME SCHOOL PACKET

Dear Parents and Students,

This school packet is meant to foster communication between you and the educational and social institutions serving your family. It provides information intended to present a general understanding of Loeys-Dietz syndrome and its maintenance.

The packet contains an area for you to enter important information and emergency contacts. It can be used in conjunction with a doctor's note or a personal note from you for more detailed information that is specific to your child. It is our hope that this will alleviate some of the discomforts of explaining a syndrome that has recently been defined. Portions of this packet should be updated as the medical/social needs of your child change.

Families often ask "how much information is necessary and who needs to know about the diagnosis?" This is an individual choice, but we do recommend that school settings, day care, and others who spend significant time caring for your child know about the diagnosis. They might not need to know all of the details, but it is necessary that they have basic information in case of an emergency. Thus, portions of this packet (including emergency symptoms and instructions) should be copied and given to institutions/people who care for your child.

It is our desire that every child or adolescent have full access to a rich educational environment and at the same time, is able to easily access the special accommodations that may be needed to allow them to be successful in their educational setting. Some children need additional assistance and/or accommodations and others do not. It is important to have good communication with your child, their teachers, principal and/or school nurses so that everyone feels comfortable and informed.

We hope you find this to be a helpful tool.

Sincerely,

The Loeys-Dietz Syndrome Foundation



LOEYS-DIETZ
SYNDROME
FOUNDATION

PO BOX 22468
BALTIMORE, MD 21203

LOEYSDIETZ.ORG

Date:

RE:

Dear Educator:

{Student first name, last name} has been diagnosed with Loeys-Dietz syndrome (LDS). The following packet of information is intended to assist communication between {Student name}, our family and the school. Included you will find emergency care information for our {son/daughter} along with some general information about LDS.

Thank you for taking the time to familiarize yourself with Loeys-Dietz syndrome on the behalf of {Student name}. As a student at your school, his/her health should be kept in mind. However, while {he/she} may have some limitations or may need some special assistance in school, {he/she} should be encouraged and supported to fully engage in your school system.

Some children need special accommodations in the classroom setting in order to be successful. We encourage our child to be honest and open about {his/her} needs and any requested support.

Our hope is that our child will be provided the best learning environment in order to empower {him/her} to lead a full and rewarding life during the school years.

If you have any questions about {Student name} or LDS, please don't hesitate to contact us. We look forward to working with you this school year.

Sincerely,

Parent's name

Contact information

NAME: _____ DATE OF BIRTH: _____

EMERGENCY CONTACT(S): _____

RELATIONSHIP(S): _____

PHONE: _____ ALTERNATE PHONE: _____

ALLERGIES: _____

GENERAL INFORMATION

LDS is characterized by aneurysms of the aortic root (the base portion of the aorta, the largest artery of the body that sends blood from the heart to the rest of the body) and throughout the arterial tree, tortuous (twisting) arteries, hypertelorism (widely spaced eyes) and uvula (piece of flesh that hangs in the back of the mouth) abnormalities. A variety of other craniofacial (head and face), skeletal, skin and cardiac findings have also been described.

Individuals diagnosed with LDS have a predisposition to develop aortic tears and ruptures at sizes not thought to be dangerous to the general population or those with other connective tissue disorders.

Surgical repair of the aorta is performed long before the individual is deemed to be at high risk for aortic tear or rupture. In most cases the student should be considered to be at a low risk for a serious event and should be encouraged to participate in school activities to the extent of their ability.

Gastrointestinal and allergic concerns can include food allergies leading to allergic responses and/or intestinal concerns including bloody stool, bowel impaction, abdominal pain and, in rare cases, intestinal or other hollow organ rupture has been reported.

In the event that this student should present

with any of the following characteristics his/her emergency contact(s) should be notified immediately and contacting the local emergency room should be considered.

- weak or unusual blood pressure
- severe pain in the head, neck, abdomen or down the back
- weakness of the limbs
- symptoms of a stroke
- dizziness
- loss of consciousness
- shortness of breath and/or difficulty breathing or speaking
- vision disturbances

Emergency services should be notified that the student has Loeys-Dietz syndrome and is at increased risk for tears of the arteries throughout the arterial tree (head through pelvis) and that imaging (CTA/MRA or echocardiogram) should be done promptly. Rarely, rupture or tear of hollow organs (spleen, intestines) may need to be investigated.

In the event of an allergic response, Benadryl should be the first line of defense as an Epi-Pen can dramatically increase blood pressure. If an anaphylaxis reaction is occurring, an Epi-Pen to treat allergic response should be used.



GENERAL MEDICAL INFORMATION

FOR STUDENTS WITH LOEYS-DIETZ SYNDROME

NAME: _____ DATE OF BIRTH: _____

PRIMARY EMERGENCY CONTACT: _____ RELATIONSHIP: _____

PHONE: _____ ALTERNATE PHONE: _____

SECONDARY EMERGENCY CONTACT: _____ RELATIONSHIP: _____

PHONE: _____ ALTERNATE PHONE: _____

ALLERGIES: _____

MEDICATIONS: _____

PRIMARY PHYSICIAN: _____

PHONE: _____ ALTERNATE PHONE: _____

OFFICE: _____

PHYSICIAN: _____ SPECIALTY: _____

PHONE: _____ ALTERNATE PHONE: _____

OFFICE: _____

PHYSICIAN: _____ SPECIALTY: _____

PHONE: _____ ALTERNATE PHONE: _____

OFFICE: _____

CURRENT MEDICAL STATUS/CONCERNS:



SCHOOL ACCOMODATIONS

FOR STUDENTS WITH LOEYS-DIETZ SYNDROME

NAME: _____ DATE OF BIRTH: _____

ACCOMMODATIONS THAT MAY BE NECESSARY FOR OUR CHILD TO BE SUCCESSFUL IN THEIR EDUCATION ARE AS FOLLOWS:

PHYSICAL EDUCATION/SPORTS NEEDS

- Modified physical education or alternative health related credit in lieu of PE
- Restrict contact sports
- Restrict tumbling or other activities that place strain on the neck or back
- Cardiovascular activities should be performed in moderation
- Avoidance of isometric exercises
- Avoidance of heavy lifting

HALLWAY/ CLASSROOM NEEDS

- Rest periods in the middle of the day for fatigue
- Periods of stretching or walking
- Two sets of books: one for home; one for school
- Preferential seating
- Allow use of a chair or pad instead of floor for circle time
- Use of elevators
- Allow passes for frequent bathroom breaks
- Allow use of book bag on wheels
- Help with note taking or use of laptop
- Provide copies of study guides or class notes
- Extra time to get to and from class (leaving before the bell)
- Extra time for timed/standardized tests, classroom tests/quizzes, and assignments
- Eliminate handwriting grade in favor of grades for content and effort
- Lockers: assign locker at eye level, allow digital lock instead of combinations locks
- Worksheets: provide copies that allow fill-in-the-blanks or underlining in lieu of rewriting existing questions/sentences
- Allow water bottle for excessive hydration

ASSISTIVE EQUIPMENT

- Chair with arms for upper body support
- Adjust chair/table height as appropriate
- Pad for chair seat or back
- Ergonomic pen/pencil grips
- Pads for wrists at computer keyboard and mouse
- Use of computers with ergonomic keyboards or Alpha Smart/NEO2

OTHER

- Use accommodations for specific allergic reactions
- Allow special snacks or other special dietary needs
- Assignment/test deadline flexibility to accommodate periodic increases in symptoms & absences
- Depending on treatment responses, a reduced class/work load until energy level improves
- Physical therapy, occupational therapy or speech therapy as necessary
- Other: _____

PARENT SIGNATURE: _____



GENERAL FACTS FOR SCHOOLS

WHAT IS LOEYS-DIETZ SYNDROME (LDS)?

Loeys-Dietz syndrome (LDS) is a genetic disorder of connective tissue that was identified and named in 2005. At that time doctors realized that even though LDS has some features of other connective tissue disorders, it is a distinct disorder. The other disorders that share features with LDS include Marfan syndrome, Ehlers-Danlos syndrome vascular type, and Shprintzen-Goldberg syndrome.

LDS characterized by aneurysms of the aortic root (part of the aorta closest to the heart) and throughout the arterial tree, tortuous (twisting) vessels, hypertelorism (widely spaced eyes) and uvula (piece of flesh that hangs in the back of the mouth) abnormalities.

A vast variety of other craniofacial (head and face), skeletal, skin and cardiac findings have also been described, but because Loeys-Dietz syndrome manifests itself in a number of ways there are never two persons with LDS that have identical medical characteristics.

All those diagnosed with Loeys-Dietz syndrome are at significant risk for dissection and rupture of arteries at sizes that are not thought to be dangerous to the general population or to those with other connective tissue disorders.

A subset of patients have orthopedic concerns, including clubfoot or flat feet, scoliosis, or cervical spine instability that are being medically monitored. The student may have had surgery, braces, and/or limitations to address these problems.

Additionally, a subset of patients have gastrointestinal complaints, including food allergies which affect the foods LDS individuals should be exposed to. Some children have G-tubes for feeding.

Learning problems are not a typical finding in Loeys-Dietz syndrome. However, due to joint laxity, some individuals may have some increased difficulty with balance and fine or gross motor skills. Due to joint laxity or gastrointestinal concerns, a child may have faster fatigue than other students.

HOW IS LOEYS-DIETZ SYNDROME DIAGNOSED?

LDS is a genetic condition, and is diagnosed through medical features and a genetic test.

HOW IS LOEYS-DIETZ SYNDROME MANAGED?

Students with LDS are under the care of multiple specialists for cardiovascular, vascular, ENT, orthopedics, allergic and/or gastrointestinal concerns.

It is likely this student is on medications to lower blood pressure and treat other symptoms. These may be taken during the school day.



GENERAL FACTS FOR SCHOOLS, *CONTINUED*

HOW DOES LOEYS-DIETZ SYNDROME AFFECT EDUCATION?

Because of the complexity of the disorder, the student may have absences due to sickness and medical appointments. In order for the student to be successful with their education they may need hospital homebound education at various times.

We thank you in advance for your support and understanding. The student should be held to the same accountability of getting assignments finished even throughout absences when correct accommodations are in place.

Dietary and exercise restrictions may come into play depending on the individual student.

WHAT SHOULD YOU DO IF YOUR STUDENT'S BEHAVIOR CHANGES?

If teachers or administration have concerns regarding a change in mood or ability, it is important to communicate with the student's family.

TO LEARN MORE ABOUT LOEYS-DIETZ SYNDROME

Find more online at the Loeys-Dietz Syndrome Foundation website at www.loeysdietz.org.



GENERAL SCHOOL GUIDELINES

HOW YOU CAN HELP

The most important thing you can do to help this student achieve success is to be understanding and informed of these things and offer support necessary to ensure that this student remains productive and comfortable in their educational and social environments.

EMERGENCY SITUATIONS

In the event that this student presents with certain medical symptoms (see emergency sheet), parents should be notified immediately and contacting the local emergency room should be considered. All school staff should be aware of these circumstances and information should be made available to emergency medical staff.

EXERCISE RESTRICTIONS

The major goal of exercise restriction is to reduce the amount of stress imposed upon the heart and other arteries. Exercise regimens that cause a sustained elevation of either heart rate or blood pressure or bring any muscle group to exhaustion should be avoided. Ensure that communication of these restrictions is clear to all school staff that have contact with this student. (See exercise restriction sheet for more specific information.) Some children with Loeys-Dietz syndrome will not be able to participate in PE classes and should be given another option that ensures academic or creative growth. Also, due to medical necessity, not participating should not interfere with graduation requirements.

PRESCRIPTION MEDICATIONS

It may be necessary for medication to be administered at school. In addition, medications may change over time. Parents are encouraged to notify school staff when changes are made and in turn, school staff are encouraged to keep the most up to date information on file.

CORRECTIVE DEVICES

There may be a need for wheelchair access or student assistance when corrective devices must be worn while attending school. If necessary, the use of an aid or student buddy should be considered when available.

ALLERGIES

Allergies have been a noted problem for young people diagnosed with Loeys Dietz syndrome. Parents are encouraged to effectively communicate the student's allergies, as well as appropriate restrictions or response actions if the student is exposed to allergens.

As a result of allergies, the student may have gastrointestinal complaints that may require easy and/or more frequent access to bathrooms. Due to some GI symptoms the child may become easily fatigued and need rest periods throughout the school day.



GENERAL SCHOOL GUIDELINES, *CONTINUED*

ORTHOPEDIC CONCERNS

Carrying heavy backpacks can negatively impact scoliosis management. It is essential that students limit the amount of weight carried. This can be achieved by allowing the student to have an additional set of textbooks to leave at home or allowing the use of a rolling book bag.

Because of loose joints causing pain/fatigue, some individuals may require more time for test-taking, shortened assignments, oral responses or access to a computer for note-taking (as typing may be a more efficient and less painful means of note-taking for the student).

MEDICAL APPOINTMENTS

Students may be absent from school more frequently due to doctor appointments and hospitalizations that are very important to maintaining health. Traveling may be necessary. Students and families are encouraged to ask for school work that can be completed during long absences to ensure that the student does not fall behind in class curriculum.

PARTICIPATION

As children age they become more cognizant of their physical or medical “differences.” The stress of diagnosis and management may take an emotional and physical toll on this young person. Young people with Loeys Dietz syndrome are encouraged to participate to their full medical ability.

Every effort should be made to ensure that this student remains comfortable in their educational environment. If this student’s behavior or interactions with other students changes it is important that the parents be notified. This will allow everyone to work together to help this student understand his/her genetic condition and achieve their full potential in a healthy environment.

During the course of a student’s learning experience their individual situation may change frequently due to medical circumstance. Families, students and schools should work together on an ongoing basis to provide the best educational experience possible.

TO LEARN MORE ABOUT LOEYS-DIETZ SYNDROME

Find more online at the Loeys-Dietz Syndrome Foundation website at www.loeysdietz.org.



EXERCISE RESTRICTIONS

GENERAL INFORMATION

The main goal of restricting the activity of those diagnosed with Loeys Dietz syndrome (LDS) is to reduce the amount of stress imposed upon the heart and arteries.

An individual with LDS should be encouraged to remain cardiovascular active. These activities work to naturally lower blood pressure and heart rate and encourage/promote cardiovascular health and fun over the lifespan.

There needs to be frank communication with the student, family and teacher regarding the requirements and intensity of PE to ensure safe student participation

If the student can maintain normal conversation during activity, this is a good indicator that activity is in a safe range.

ACTIVITIES THAT SHOULD BE AVOIDED

IT IS A GENERAL RULE TO RECOMMEND THAT THOSE DIAGNOSED WITH LOEYS-DIETZ SYNDROME AVOID:

- a sustained heart rate of above 140
- exercises that involve straining any muscle group to the point of exhaustion.

DISCOURAGED ACTIVITIES INCLUDE, BUT ARE NOT LIMITED TO, THE FOLLOWING;

- competitive exercise performed to the point of exhaustion
 - running sprints
 - strenuous contact sports where there is a high risk of a sharp blow to the body
 - isometric exercise (including fitness tests) that involves muscle straining such as weight lifting, chin ups, rope climbing, sit ups and other activities in which a muscle group is brought to exhaustion
 - tumbling and gymnastics due to the risk of cervical spin instability
-

ACTIVITIES THAT SHOULD BE ENCOURAGED

Routine activities in Physical Education programs that encourage moving activities performed for fun and in moderation as part of a healthy lifestyle should be encouraged as they naturally lower heart rate and blood pressure over time.

In most circumstances those diagnosed with Loeys Dietz syndrome are encouraged to participate to the extent of their abilities in any activity that involves movement in the absence of muscle straining or a sustained elevation of blood pressure or heart rate.

If there are questions or concerns about PE activities, please provide the family with an outline of activities that they can get reviewed by their cardiologist for approval.



EXERCISE RESTRICTIONS, *CONTINUED*

ACTIVITIES THAT SHOULD BE ENCOURAGED

ENCOURAGED ACTIVITIES INCLUDE, BUT ARE NOT LIMITED TO, THE FOLLOWING;

- regular aerobic exercise preformed in moderation, such as swimming, bike riding, hiking, jogging and tennis, etc.

PARTICIPATION

When participation in physical education is inappropriate, every effort should be made to maximize the potential of the student by allowing them to explore other endeavors. Simply sitting on the side lines may cause a disturbance in their educational and social development and is not a viable option.

TO LEARN MORE ABOUT LOEYS-DIETZ SYNDROME

Find more online at the Loeys-Dietz Syndrome Foundation website at www.loeydietz.org.