



Sample School Plans and Letters

Letter to School

Doctor Verification Letter

Individual Health Plan

Section 504 Education Plan

Emergency Care Plan

Accompanying this school resource kit are various letter and plan templates to assist both parents and school staff in developing their own versions. The enclosed documents demonstrate how the needs of a student with cardiomyopathy can be addressed through a comprehensive set of plans once the school has been informed of the diagnosis. Each template should be adjusted to reflect the symptoms, risks and needs of a child's particular form of cardiomyopathy.

Letter to School and Doctor Verification Letter3

Purpose: Informs the school of a child's diagnosis as verified by a physician and requests a meeting for further discussion of a child's needs.

When to use it: Send upon diagnosis or when a child begins a new school.

Who receives it: Principal.

Individual Health Plan4

Purpose: Describes the student's medical, social and academic situation as well as issues to take into consideration during the school day.

When to use it: Pass to school staff as a summary of a child's situation or work with the school nurse to create an abbreviated plan. In some cases, the health plan takes the place of a Section 504 plan and lists the accommodations that will be provided to the student.

Who receives it: School nurse.

Section 504 Education Plan7

Purpose: Outlines specific medical accommodations, educational aids and services that a student needs to function within the school setting. Alternately, students eligible for special education will have this information in an Individualized Education Plan (IEP).

When to use it: Distribute to key school personnel before the beginning of the school year and schedule a meeting with plan participants to confirm modifications and/or accommodations.

Who receives it: Parents, teachers and other school staff that come in contact with the child.

Emergency Care Plan 10

Purpose: Provides a step-by-step plan with easy-to-read directions on how to handle an emergency situation such as sudden cardiac arrest. The plan should be created with input from the child's physician and include information about the child's medical condition, treatment, emergency contacts, warning signs requiring medical attention and appropriate interventions.

When to use it: Distribute at the beginning of the school year and check periodically that it is updated.

Who receives it: All school staff that supervise the student, including substitute teachers.

Letter to School

Date

Dear Principal **(Name)**:

My child, **(Name)**, has **(Type of Cardiomyopathy)**. Cardiomyopathy is a chronic and sometimes progressive disease of the heart muscle, which affects the heart's ability to pump blood effectively. Sudden cardiac arrest can be a risk associated with the disease **(Modify according to your child's form of cardiomyopathy and risk factors)**.

Although **(Child's Name)** may appear healthy, the symptoms of cardiomyopathy are extremely variable and may change at different stages in life. Fatigue, physical education and exercise restrictions, side effects from medication, psychosocial concerns, and absences due to medical appointments are issues that may affect **(Child's Name)** during the school year.

(Child's Name)'s education is very important to me. I would like to arrange a meeting with you in order to talk about **(his/her)** medical condition and school accommodation needs. I would like to work with the school to develop a suitable education and medical emergency plan that will ensure a safe learning environment for **(him/her)**. It would be helpful if **(Child's Name)**'s teachers, the special education coordinator, school nurse, gym instructor and **(Any others needed)** could participate. I would like to set up this meeting in **(Month or Week)** and can be reached at **(Phone Number)**.

Thank you for your understanding. I look forward to speaking to you and working together in the coming school year.

Sincerely,

Parent's Signature

Parent's Name

Parent Contact information

Doctor Verification Letter

Date

To Whom it May Concern:

This is to confirm that **(Child's Name)** is diagnosed with **(Type of Cardiomyopathy)**.

Cardiomyopathy is a chronic disease of the heart muscle, which affects the pumping action of the heart. Depending on the severity of the disease, children with cardiomyopathy may need to take medication, may have an implantable pacemaker or defibrillator, and may require restrictions on physical activity and sports. **(Elaborate on child's current treatment and any special care requirements or restrictions)**. If **(Child's Name)** experiences any symptoms such as chest pain, irregular breathing, fainting, change in skin color or decreased level of consciousness, a pediatric cardiologist should be notified immediately.

Sincerely,

Physician's Signature

Physician's Name

Physician Contact Information

Individual Health Plan

Date: 9/1/09

Student Information

Name: Amy Jones
Date of Birth: 9/9/1995

Homeroom Teacher: Mrs. Green
Grade: 8th

Contact Information

Parent(s)/Guardian(s):

Father: Bob Jones
10 Lake Road
Springfield, NJ 01234

Home: 555-555-5552
Work: 555-555-5553
Cell: 555-555-5551

Mother: Mary Jones
10 Lake Road
Springfield, NJ 01234

Home: 555-555-5552
Work: 555-555-5555
Cell: 555-555-5550

Alternative Emergency Contact:

Grandparents: Ron and Jane Smith
45 Oak Street
Chatham, NJ 07670

Home: 555-333-2345
Cell: 555-333-2455

Physician Information

Pediatrician: Samuel Smith, MD

Phone: 555-555-5556

Pediatric Cardiologist: Bonnie Brown, MD

Phone: 555-555-5557

Electrophysiologist: Christine Park, MD

Phone: 555-555-5454

Geneticist: James Lopez, PhD

Phone: 555-555-5558

Hospital Preference: Children's Hospital

Phone: 555-888-8300

Health Insurance Carrier: Cared Health Insurance
Policy Number: AB12345-67C

Phone: 800-333-1000

Health Condition

Diagnosis: Dilated Cardiomyopathy

Description of Diagnosis:

Dilated cardiomyopathy is a chronic disease of the heart muscle in which an abnormally enlarged heart is unable to function properly and pump enough blood through the body. Irregular heartbeats (arrhythmia) and heart failure may occur as a result. While the disease can progress rapidly and be life-threatening, Amy is currently in stable condition with medication. More information on the disease can be found at www.childrenscardiomyopathy.org.

Medical History:

- Age at diagnosis: 2 years
- Surgeries: an implantable cardioverter defibrillator (ICD) was implanted on 7/14/07
- Allergies: none

Current Status & Care Management

Frequency of evaluations:

Amy sees a pediatric cardiologist and electrophysiologist every 4 months.

Current Medications:

Lasix 10mg at 10am, Carvedilol 12.5 mg at 10am and 2pm, and Enalapril 7.5mg at 10am and 2pm. Side effects may include dizziness, fainting, difficulty concentrating, fatigue, risk of dehydration and frequent urination. Over-the-counter medication should be cleared by Amy's cardiologist for compatibility with current heart medications.

Special Post Surgical Care:

Due to her implantable defibrillator, Amy should avoid contact sports and strong electrical or magnetic fields. Amy's ICD has a built in alarm that will beep if it is too close to a magnetic source, the battery is depleted or there is a problem with the ICD lead.

The following should be kept at least 12" away: magnetic wands used by airport security and Bingo games, battery powered cordless power tools (i.e. screwdrivers and drills), anti-theft devices at libraries or department stores, transmitting antennas (i.e. stereo speakers from large systems, transistor radios, boom boxes), engine alternators and cellular phones.

Dietary Restrictions & Feeding:

Amy's stomach is easily upset so she should eat smaller meals more frequently.

Activity Tolerance & Restrictions:

Amy is restricted from participating in competitive sports and engaging in strenuous physical activity that will increase her heart rate and risk for sudden death. She also should not engage in strenuous isometric activities (e.g. weight lifting, rope climbing, straining, anything that causes her to grunt or hold her breath). Some recreational play is okay, but her physical education classes should be modified. Additional points to consider:

- She should not do push-ups or pull-ups past the point of ease.
- She should avoid contact sports that could impact her ICD site.
- Her heart rate should not exceed 150 or be under 65.
- Amy fatigues easily because of the disease and the side effects of her medication.
- If she tires, she should be permitted to rest until she is ready to continue; she should not be told to ignore symptoms or to continue exercising.
- She should avoid staying outside when temperatures are extremely hot or cold (over 85 degrees or under 35 degrees).

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Emergency Care

Amy is at risk of sudden cardiac arrest and requires an emergency plan for possible cardiac/respiratory arrest or a shock from her ICD.

Psychosocial Status

Student's Acceptance of Disease and Understanding of Health-Care Needs:

Amy has no behavioral issues related to her diagnosis. She understands her diagnosis, her medication routine and her activity limitations. She does need encouragement with adhering to her exercise restrictions, however.

Participation in School, Community & Family Activities:

Amy is involved in school chorus and takes piano and art lessons outside of school.

Student's & Family's Coping Methods:

Amy uses drawing as an outlet for her feelings related to the disease. Amy is especially comfortable speaking with her art teacher Miss Lee. She also feels comfortable asking questions with her pediatric cardiologist Dr. Brown. The family has visited a family therapist in the past.

Academic Issues

Academic Achievement:

Amy has consistently received B's and C's on her report cards in the past. Frequent absences have caused her to struggle with classwork more recently.

School Attendance Pattern:

Amy has had more frequent and longer absences than her classmates due to colds or stomach viruses affecting her more severely. Amy must miss a large portion of a school day every four months in order to see her cardiologist and electrophysiologist.



Section 504 Education Plan

This plan was developed under Section 504 of the Rehabilitation Act of 1973 (Section 504), the Americans with Disabilities Act (ADA), and the Individuals with Disabilities Education Act (IDEA) to identify the student's healthcare-related needs as well as accommodations, services and support to be provided.

The purpose of this plan is to optimize the student's participation in his/her academic curriculum and educational goals, aid in the management of his/her illness, and reduce the student's concerns in the school environment.

School Year: 2009–2010
Student: Amy Jones
Grade: 8th

School: Gladys Wallace Middle School
Date of Birth: 9/9/1995

Plan Participant Names:

Anita Starr
Josh Frances
Patricia Lutz *
Jeannine Green
Bob and Mary Jones
Elise Baker
Todd Gonzales

Title:

Principal
School Nurse
Special Education Coordinator
Grade 8 Homeroom Teacher
Parents
School Counselor
Gym Instructor

Plan Coordinator (*):

The Plan Coordinator will be responsible for carrying out the provisions of this plan as well as serving as the liaison between the student, his/her family and the school personnel. This will involve understanding pediatric cardiomyopathy, the treatments the student is receiving, the side-effects of the treatments, and the student's particular symptoms and needs.

Description of the disability and how it affects the student's access to or participation in school programs and/or facilities:

Disease Description:

Amy has dilated cardiomyopathy, a chronic disease of the heart muscle in which an abnormally enlarged heart is unable to function properly and pump enough blood through the body. Irregular heartbeats (arrhythmia) and heart failure may occur as a result. While the disease can progress rapidly and be life-threatening, Amy is currently in stable condition with medication. More information on the disease can be found at www.childrenscardiomyopathy.org

Signs & Symptoms:

Signs and symptoms of cardiomyopathy may change over time and worsen in an unpredictable manner. Common signs and symptoms include:

- breathlessness (with exertion or at rest)
- swelling of the legs, ankles, feet
- bloating of the abdomen
- fatigue
- poor appetite and frequent upset stomach
- irregular heartbeats (rapid, pounding or fluttering sensation)
- chest pain
- dizziness, lightheadedness and fainting

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Section 504 Education Plan continued

Amy's current symptoms include poor appetite, frequent upset stomach, difficulty breathing with exertion and abnormal heart rhythms. Due to her diagnosis, Amy is slightly underweight for her age and she fatigues easily.

Treatment & Medical Management

Amy is taking 3 cardiac medications to manage her symptoms:

- Lasix 10 mg at 10am (causes frequent urination and risk of dehydration)
- Carvedilol 12.5 mg at 10am and 2pm (causes difficulty concentrating and fatigue)
- Enalapril 7.5 mg at 10am and 2pm (causes dizziness)

Over-the-counter medications should be checked by Amy's cardiologist for compatibility with current cardiac medications before being administered.

Amy had an automatic implantable cardioverter defibrillator (ICD) implanted on 7/14/07 to protect her from life-threatening cardiac arrhythmias (abnormal heartbeats).

Amy is restricted from participating in competitive sports and engaging in any strenuous physical activity that may increase her heart rate and risk for sudden death. Contact sports that could cause impact to her chest and implantable defibrillator should not be permitted.

Amy visits her pediatric cardiologist and electrophysiologist every 4 months, which requires her to miss a half day of school.

Because of the compromised functioning of her heart, illnesses have a more serious effect on Amy. Therefore, Amy should avoid classmates who appear sick, and her parents should be notified of any serious infectious disease or outbreak.

Details of the supplementary aids and services, modifications, accommodations and/or placement considerations that are necessary for the student to access school programs and/or facilities:

Emergency Preparation:

- A copy of this Section 504 plan and emergency care plan should be distributed to all teachers and substitutes that Amy has daily contact with.
- Key school personnel should be selected to be CPR and AED trained.

Physical Activity:

- A list of activities performed in gym class should be provided for clearance by Amy's cardiologist, and a plan should be developed for modifying physical education activities. Amy will self-monitor her energy level and fatigue during gym class.
- Due to Amy's implantable defibrillator, she should avoid contact sports and strong electrical or magnetic fields. The following should be kept at least 12" away: magnetic wands used by airport security and Bingo games, battery powered cordless power tools (i.e. screwdrivers and drills), anti-theft devices at libraries or department stores, transmitting antennas (i.e. stereo speakers from large systems, transistor radios, boom boxes), engine alternators and cellular phones.
- Recess periods should be monitored at all time by a CPR trained individual. Amy should be permitted to stay inside during recess in extreme weather (over 85 degrees or under 35 degrees) to play board games. One other student should be permitted to stay inside with Amy to keep her company.

School & Classroom:

- Letters should be sent to parents of all 8th grade students informing them that a classmate has a weakened immune system. The letter will remind parents that any child with an infectious illness should not be sent to school.
- Hand sanitizer dispensers should be installed at the doorway to each of the classrooms Amy uses.
- Amy should receive a pass to visit the nurse between first and second periods (around 10 am) and fifth and sixth periods (around 2 pm) to take her medication.
- The school nurse should provide Amy with a place to rest if she feels fatigued during the school day.
- Amy should be permitted to eat two high calorie snacks during the day and to drink water in the classroom.
- Amy should be allowed to use the rest room more frequently without asking permission.
- Amy's classes should be grouped in one area of the school or scheduled to minimize walking distance. Amy will be permitted to use the school elevator, when needed, to get to classes held on different levels.
- Amy should be permitted to have and store extra sets of relevant books at home.

Academic:

- Amy should be given time and a half to complete timed tests.
- Amy should not be penalized for tardiness or absences resulting from her disease.
- Amy should be given assistance to help her make up any classroom time due to absences from doctor visits, procedures or disease complications. The Plan Coordinator will ensure that the teacher provides lesson plans, copies of visual aids and written homework assignments. If necessary, the teacher will assign a note-taker. The Plan Coordinator will make arrangements with Amy's parents to get these materials to Amy and develop a plan for making up her exams and completing her projects without penalty.

- If Amy is absent from school for an extended period of time (i.e. more than 7 consecutive school days), the Plan Coordinator should make the necessary in-home or hospital tutoring arrangements. When Amy returns to school, the Plan Coordinator should assist her in working with her teacher(s) to catch up with her school assignments.

Other modifications that may be required based on a child's disease severity:

These additional points may be added if necessary.

- Shortened school day or week due to fatigue
- Rest periods scheduled during the school day
- Harder classes scheduled at student's "best" time of day
- A peer buddy assigned to the same class to help with psychosocial adjustment and to prevent bullying
- Modifications related to diet and tube feeding needs
- Post-surgery precautions following a myectomy or ICD implantation
- Post-surgery precautions following a heart transplant
- Plan for informing classmates about cardiomyopathy (if the student consents)

Emergency Care Plan

Date: 9/1/09

Name: Amy Jones

Date of Birth: 9/9/1995

Medical Condition: Cardiac Disorder

Medication: Lasix 10mg at 10am, Carvedilol 12.5 mg at 10am and 2pm, and Enalapril 7.5mg at 10am and 2pm

Surgery: Implantable Cardioverter Defibrillator (ICD) implanted on 7/14/07

Allergies: None

Homeroom Teacher: Mrs. Green

Grade: 8th

Diagnosis: Dilated Cardiomyopathy

Emergency Risks: Sudden Cardiac Arrest

Warning Signs & Symptoms

- Decreased level of consciousness
- Shortness of breath
- Alteration in speech, vision, hearing, coordination, balance
- Fatigue or marked weakness
- Rapid, slow, irregular heart rate
- Pale or bluish skin color
- Chest pain or pressure
- Clammy, cool skin
- Sluggishness or unresponsiveness
- Fainting or dizziness
- Numbness or tingling
- Trembling, seizures
- Swelling of abdomen, legs, feet
- Headache
- Vomiting
- Fast, weak pulse
- Poor appetite

Emergency Protocol

If student experiences any of the above symptoms but is conscious, alert and in no apparent urgent distress:

- Notify school nurse
- Assist student to comfortable seated or lying position
- Have student take slow deep breaths and relax as much as possible
- Once student has stabilized, escort him or her to the school nurse; the student should not be sent anywhere alone when having symptoms
- Call parent or grandparents if parents are unreachable

If student is unconscious or unresponsive, faints, has above or below normal pulse, has difficulty breathing that does not improve with rest, or is shocked by her ICD:

- Send someone, call or intercom front office to call 911 immediately
- Send someone else to retrieve the Automatic External Defibrillator (AED), kept in a case by the front entrance

- Call or intercom school nurse and nearest CPR/AED trained staff
 - Josh Frances, School nurse (ext. 5342)
 - Todd Gonzales, Gym Instructor (ext. 5343)
 - Patricia Lutz, Special Education Coordinator (ext. 5344)
 - Jeannine Green, Grade 8 Homeroom Teacher (ext. 5345)
 - Larry Conrad, Librarian (ext. 5346)
- Front office to notify parent
- Office staff to wait in front to meet emergency responders and escort them to the correct location in the building
- School employee to send all students into the hallway or a nearby classroom
- Monitor Airway, Breathing, and Circulation
- Until AED machine arrives, administer CPR if necessary
- When available, start AED machine, apply pediatric AED pads, and follow AED machine instructions
- Provide this emergency plan to the emergency responders

Family Contact Information

Relative	Home Phone	Work Phone	Cell Phone
Bob Jones (father)	555-555-5552	555-555-5553	555-555-5551
Mary Jones (mother)	555-555-5552	555-555-5555	555-555-5550
Ron and Jane Smith (grandparents)	555-333-2345		555-333-2455

Note: If family member is unreachable, call pediatric cardiologist.

Medical Contact Information

Physician	Name	Phone
Pediatrician	Samuel Smith, MD	555-555-5556
Pediatric Cardiologist	Bonnie Brown, MD	555-555-5557
Electrophysiologist	Christine Park, MD	555-555-5454
Hospital Preference	Children's Hospital	555-888-8300
Health Insurance	Cared Health Insurance (#AB12345-67C)	800-333-1000

Note: Amy has a medical alert bracelet. Additional health history information can be obtained by calling the number on the bracelet.

These templates were created to serve as reference materials for families, caregivers, and school personnel. The material presented is not intended to be complete or serve as medical advice. These examples may not address every need that a child with cardiomyopathy requires in school. In addition, schools may have different ways of developing, maintaining, distributing, naming, and documenting plans and accommodations.

The provided information should not be a substitute for consultation with a qualified health care professional who is more familiar with a child's individual medical conditions and needs. A child's medical situation may vary depending on the type of cardiomyopathy diagnosed, cause, and severity. Each child's plan should be created with his or her specific needs in mind and in consultation with his or her physician.

**For more information, visit
www.childrenscardiomyopathy.org.**



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**866.808.CURE
info@childrenscardiomyopathy.org**