

SUPPLEMENTAL MATERIAL

18 Key Intervention Domains

| | Domains | Descriptions | Examples |
|-------------------------|----------------------------------|---|---|
| School Health | 1. Attendance | Number of absences so far this school year, concerns about attendance, and planned future hospitalizations | |
| | 2. Self-Limit Activities | Ability to take breaks as needed without being told | |
| | 3. Strength | Body and muscle power, motor skills, tiredness, and the capacity to perform school-related physical activities | <i>Limitations</i> – struggles to sit, stand, hold a pencil, or use other classroom tools for extended time periods; tires easily, needs frequent rest breaks, or falls asleep at school |
| | 4. Vitality | Energy, liveliness, endurance, and the ability to sustain prolonged mental or physical effort | <i>Limitations</i> – mental fatigue, low energy/mood, flat affect, limited participation, social withdrawal, or difficulty standing/walking for extended time/distance <i>High/Low</i> – vitality is limited if it is reduced or heightened, as with hyperactivity |
| | 5. Alertness | Ability to maintain attention, focus, and concentration | <i>High/Low</i> – alertness is limited if it is reduced or heightened, as with hypervigilance |
| Developmental Progress | 6. Adaptive Functioning | Ability to independently complete developmentally-appropriate self-care tasks | <i>Skills</i> – self-feeding, toilet training, independent dressing, maintaining basic safety, and communicating when feeling unwell |
| | 7. Sensory Processing | Ability to process sensory input with typical response to stimuli | <i>Potential Triggers</i> – loud/sudden noises, background noises, bright lights, specific food tastes/textures/smells, physical touch/body pressure, sensitivity to smells/fragrances, temperature sensitivity, crowds, and transitions <i>High/Low</i> – sensory processing is atypical if it is heightened or reduced, as with high pain tolerance (low pain sensitivity) |
| | 8. Fine Motor Skills | Small muscle movements, strength, and coordination of the hands and fingers | <i>Activities</i> – handwriting, using scissors and faucets, opening doors and packages, tying shoes, using buttons and zippers, turning combination locks, and hand-eye coordination |
| | 9. Gross Motor Skills | Large movements with arms, legs, feet, or entire body | <i>Activities</i> – walking and running with coordination, climbing stairs with alternating feet, and throwing/catching a ball |
| | 10. Language Development | Speech, hearing, and communication skills | <i>Language Skills</i> – articulation, expressive, receptive, and pragmatic |
| Psychosocial Adjustment | 11. Social Skills | Friendships and appropriate interactions with adults and peers | <i>Skills</i> – establishing and maintaining genuine friendships, playing with peers (versus alongside them), and interacting appropriately with teachers |
| | 12. Emotional Functioning | Ability to express and manage emotions, ask for help, cope with medical condition and treatment, and self-confidence | <i>Dysfunctions</i> – anxiety, depression, panic attacks, social withdrawal, and suicidal thoughts or self-harm behaviors |
| | 13. Behavior | Communicating appropriately, exercising self-control, following rules, and mentally transitioning | <i>Challenges</i> – impulsiveness, tantrums, perseverating, dishonesty, and verbal/physical aggression |
| | 14. Executive Functioning | Planning, organization, and memory | <i>Skills</i> – task management (initiation, prioritization, and completion), following multi-step instructions, decision-making, reasoning, judgment, problem solving, independence, goal achievement, and mental flexibility |
| Academic Skills | 15. Reading | Comprehension, decoding, stamina, and fluency | <i>Pre-Reading Skills</i> – word-to-word matching, letter identification, reads left-to-right, turns pages right-to-left, understands concepts of beginning/middle/end, and recalls details of story (characters, colors, places, etc.) |
| | 16. Writing | Handwriting legibility/fatigue, forming sentences and paragraphs, spelling, grammar, developing ideas, adding details, and citing supportive evidence | <i>Pre-Writing Skills</i> – tracing, drawing pictures to match words/ideas, and letter formation |
| | 17. Math | Addition/subtraction, multiplication/division, mental math, word/story problems, telling time, counting money, making change, problem solving, measurements, and understanding abstract math concepts | <i>Pre-Numeracy Skills</i> – number identification, counting numbers in sequence, determining bigger/smaller, 1:1 correspondence, and understanding patterns |
| | 18. Other Subjects | Science, social studies, physical education (gym), art, music, theater, computer sciences, foreign language, and other electives | |



**Educational Achievement
Partnership Program**

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| Patient/Student: | | PATIENT NAME | |
|------------------------------|-----------------------|-----------------|------------|
| Date of Birth | 00.00.0000 | Age | 00 Years |
| Primary Service Line | XX | Last visit date | 00.00.0000 |
| Primary Diagnosis | Primary Diagnosis | | |
| Neuropsychological Diagnoses | ND Dx | | |
| School Name | | XXXX | |
| 2021-2022 Grade Level | X th Grade | | |
| Education Plan | IEP/504 Plan | Date revised | 00.00.0000 |
| Category | XXX | | |
| School Health Plan | Yes/No | Date revised | 00.00.0000 |

Letter Date

To: **NAME**, School Psych / SPED Teacher
SCHOOL NAME
SCHOOL ADDRESS
 Phone: **PHONE #**
 Email: **EMAIL ADDRESS**

CC: **NAME**, School/District Nurse
 Phone: **PHONE #**
 Email: **EMAIL ADDRESS**

NAME, School Psych / SPED Teacher
 Phone: **PHONE #**
 Email: **EMAIL ADDRESS**

Parent/Guardian
 CC: **NAME**, Parent/Guardian
 Phone: **Phone #**
 Email: **Email Address**

Medically-Informed Education Plan Referral & Health Recommendations

Dear **SCHOOL PSYCHOLOGIST**, **SPECIAL EDUCATION TEACHER** and **SCHOOL NURSE**, **[ADD ADMINISTRATOR AS NEEDED]**

Children’s Wisconsin (CW) provides care coordination services that extend far beyond the walls of the hospital to maximize quality of life for patients. Our *Education Achievement Partnership Program (EAPP)* collaborates with patients’ schools to address the many known educational risk factors for children with underlying health conditions. EAPP staff are experienced educators, specially trained in the impacts of medical conditions, surgeries, treatments, and complications on physical and mental health, neurodevelopment, and learning.

Through collaborative partnership with the EAPP, school staff are key stakeholders on interdisciplinary care teams that include the patient’s family and entire hospital team of medical specialists, psychologists, social workers, child life experts, and educational partners. You are receiving this letter today about **PATIENT NAME** because our team feels strongly about care coordination and ensuring our shared patient/student has access to all of the support services necessary to thrive in an academic setting. **PATIENT**’s medical team prepared this letter describing **his/her** medical condition and recommendations for school health and learning supports.

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I. Medical Overview

PATIENT is followed by the XX Clinic at Children’s Wisconsin to address a series of **chronic** and **acute** medical conditions and resulting neuropsychological limitations. The key aspects of PATIENT’s medical and neuropsychological history are described below.

A. Medical Conditions

| Diagnoses | Descriptions | Interventions & Medications |
|--|--|---|
| Primary Dr. First Last (414) 266-XXXX | (give example of the concern and describe in layman’s terms) (Example: Oxygen-Poor Blood – due to holes in the internal heart wall of the heart, oxygen-depleted blood (blue, right side) mixes with oxygen-rich blood (red, left side), resulting in delivery of mixed oxygen-poor blood (purple) to the brain and body.) | Patient had a stent placed in the heart to increase blood flow on 1/2006. |
| Secondary Dr. First Last (414) 266-XXXX | [Example] Asthma is a disease that affects the lungs and can last a lifetime. Even if asthma symptoms are not active, asthma is still there. When an asthma attack happens, the airways become swollen, make more mucous, and the muscles around the airways squeeze tight, restricting air flow. | There is no cure for asthma, but PATIENT has several treatment medications and equipment to manage symptoms: <ul style="list-style-type: none"> – [MED NAME]: a daily controller medicine (inhaler) – [MED NAME]: a quick relief (rescue) medicine (inhaler); 2 puffs as need with symptoms and before exercise/sports – Spacer Device: used with metered dose inhalers to improve medicine delivery to the lungs – Nebulizer Machine: turns liquid medicine into breathable mist |
| Tertiary | | |
| ADD AS NEEDED | | |

PATIENT’s extensive surgeries help restore heart function, but do not “cure” congenital heart disease. It is our clinical impression that PATIENT is doing well from a medical standpoint at this time; however, s/he remains closely monitored by our hospital care team. Possible symptoms, response steps, and related accommodations are included in the “School Healthcare Guidelines” at the end of this letter [OR] documented in PATIENT’s current School Health Plan, last revised on XX.XX.2021 and are not repeated herein.

B. Neuropsychological Overview

Medical conditions such as (NAME OF CONDITION) and other pediatric disease processes affect blood-oxygen circulation in the body, and may cause symptoms such as (NAME SYMPTOMS [cardiac symptoms: irregular heart rate, breathing disturbances, low energy, fatigue]), and impact PATIENT’S overall **strength, vitality, and alertness**. Many congenital disease processes are known to affect normal blood and oxygen flow, potentially delaying pre-and post-natal **brain development**. Children with complex medical histories and impacting conditions often score lower in areas such as hand-eye coordination, fine and gross motor skills, social-emotional functioning, and language development than their typically developing peers. Behavior, attention, immaturity, and learning challenges are also much more common among children with (NAME CONDITION) than their healthy peers.

Extensive research demonstrates educational concerns may arise at different stages of development from preschool through adulthood as independence, organization, and academic skill level demands increase and the child’s abilities remain delayed. Subtle neuropsychological deficits affecting multiple domains are extremely common and often result in compounded educational concerns over time as these neuropsychological deficits do not self-correct and these children cannot simply “catch-up” on their own without some level of intervention.

(Use only if had an ND) PATIENT received a formal neuropsychological evaluation on DATE. This assessment included interviews, observations, and completion of both formal and informal tasks and pencil and paper-based testing. The evaluation revealed the diagnoses and impairments listed below.

(Use if NO ND) PATIENT’s medical records report the following neuropsychological delays and considerations.

| Diagnoses & Considerations | Descriptions & Examples |
|-----------------------------|--|
| Cognitive/Processing | – List & describe deficits from medical/school records, Parent/Teacher Interviews, outside provider records/consultation, etc. |
| Learning | – |

| | |
|-------------------------------------|---|
| Developmental | - |
| Speech | - |
| Fine Motor | - |
| Gross Motor | - |
| Sensory | - |
| Attention | - |
| Behavior | - |
| Executive Functioning | - |
| Social/Emotional Functioning | - |
| Adaptive Functioning | - |

(Use only if had an ND) Academic recommendations following this neuropsychological evaluation stated that PATIENT may benefit from receipt of intervention services in (LIST AREAS), and additionally that more intensive support provided through a Multi-Tiered System of Support (MTSS) or through the provision of special education services as related to (LIST CATEGORY OHI, SLD, etc.) may be appropriate for PATIENT based upon his/her medical history and neuropsychological deficits that directly impact educational achievement and social-emotional development.

II. **Education Plan Re-Evaluation Request**

Based on a combination of PATIENT's chronic medical conditions, neuropsychological sequelae, comorbidities, and educational performance challenges, PATIENT's medical team formally requests SCHOOL NAME: **[CHOOSE REQUEST and DELETE other options/numbers]**

1. **review** PATIENT's current Individualized Education Plan to determine if the recommended revisions are necessary.
2. **reevaluate** PATIENT's eligibility for an Individualized Education Plan to determine if s/he qualifies under additional areas of impairment and/or for the recommended special education services/aids.
3. **evaluate** PATIENT's eligibility for an Individualized Education Plan to determine if s/he qualifies under the category of Other Health Impairment and XX (ADD AS APPROPRIATE) for the recommended special education services/aids.
4. **evaluate** PATIENT's eligibility for an Accommodation Plan under Section 504 of the Rehabilitation Act of 1973.
5. **reevaluate** PATIENT's Section 504 Accommodation Plan to determine if the recommended supports are necessary.

Due to chronic **and acute** health impairments and corresponding symptoms, side effects, and complications, we strongly believe PATIENT may be adversely affected on a daily basis in many areas of learning and classroom performance. For reference, examples of PATIENT's disability-related limitations, areas of intervention, **and** recommended supports are outlined below.

A. Disability Limitations

Based on our findings over multiple observations, we expect PATIENT will continue to consistently experience these limitations and challenges in all environments: at home, school, and in the community.

| Limitations | Descriptions & Examples |
|------------------|--|
| Strength | - Include examples from Parent Interview, Teacher Interview, Nurse Survey, Medical Records, etc. |
| Vitality | - |
| Alertness | - |

B. Education Plan Recommendations

To address **PATIENT**'s disability limitations, neuropsychological deficits, and educational intervention needs, the medical team requests **SCHOOL NAME** consider incorporating provision of the following services, aids, and/or accommodations into **PATIENT**'s education plan.

To facilitate skill growth and generalization, consider providing special education and/or therapy services in both pull-out and integrated classroom settings.

Following thorough evaluation, if **SCHOOL NAME** determines **PATIENT** is ineligible for education plan-based services/accommodations, the areas of intervention outlined below should be addressed through a Multi-Tiered System of Support (MTSS).

| Areas of Intervention — Examples | Current Levels of Intervention (__ min., __ time(s) per week/month) | Services | Recommended Supplemental Aids & Accommodations |
|--|--|---|--|
| Academic Achievement — Reading: — Writing: — Math: — Other: | Reading Services: Writing Services: Math Services: Other Academic Services: | [Example] Reading Services: increase 1:1 service time. [Example] Writing Services: provide tutoring services before, during, or afterschool. [Example] Math Services: design services and goals to promote independent performance growth (not just supported skill development). [Example] Other Academic Services: provide co-taught history and biology classes. [Example] Collaboration with Teachers: schedule time biweekly special education and general education teachers to discuss skill development and academic planning for management upcoming curriculum, tests, and projects. | |
| Classroom Performance — Executive Functioning: | Study Skills: | [Example] Study Skills Class: schedule daily 1:1 intervention time with the special education teacher to support executive functioning, organization, and assignments/test-prep. | |
| Social/Emotional Functioning — Social: — Emotional: | Social Skills: | [Example] Social Skills Class: schedule weekly intervention time with the school psychologist/counselor to address school-related social/emotional concerns and/or participation in a structured social skills class. | |
| Behavior — Behavior: — Adaptive Behavior: | Behavior Services: Adaptive Behavior Services: | [Example] Behavior Services: create and implement a Behavior Intervention Plan. | |
| Communication — Speech: — Hearing: | Speech Therapy: Audiology Services: | [Example] Speech Therapy: continue service time and connect services to _____ (specific goal area). [Example] Audiology Services: begin services and connect them to _____ goal/skill development. | |
| Motor Skills — Fine: — Gross: | Occupational Therapy: Physical Therapy: | [Example] Occupational Therapy: consider providing both push-in services and services outside of the general education classroom. [Example] Physical Therapy: begin services and connect them to _____ goal/skill development. | |

| | | | |
|--|--|--|--|
| Vocational Skills – <u>Work/College Readiness:</u> | Vocational Services: | [Example] Vocational Services: create and implement a transition plan that includes preparation for college. | |
| Other – <u>Vision:</u> – <u>Transportation:</u> – <u>Other (Describe):</u> | Vision Services: Transportation Services: | [Example] Transportation Services: provide door-to-door bussing services. | [Example] Vision Aids: provide seating near the front of the classroom. |
| Medical/Health – <u>Symptom Management:</u> – <u>Medications:</u> | School Nurse Services: Skilled Nursing Services: Medication Management: | [Example] School Nursing Services: schedule annual consult time for discussing health updates with the family/medical team, creating/ updating a comprehensive School Health Plan, and educating teachers/staff about diagnoses, symptoms, precautions, etc. [Example] Skilled Nursing Services: provide 1:1 nursing services for G-Tube operation according to PATIENT 's feeding schedule. [Example] Medication Management: 10 min./day for inhaler use prior to P.E. class and after school sports. [Example] School Health Collaboration: conduct an annual health update meeting with school/district nurse, family, a medical team representative, and relevant teachers/staff members to review PATIENT 's School Health Plan and educate staff about PATIENT 's diagnoses, symptom management guidelines, precautions, etc. | |

III. School Healthcare Guidelines

**** School staff should call 9-1-1 at their own discretion for any concerning symptom. ****

PATIENT's annual school health plan should address the following guidelines for **XX (DIAGNOSIS SPECIFIC)** symptoms, safety, and activities.

A. Symptom Management Guidelines

CARDIAC SYMPTOM MANAGEMENT

| | Cardiac Symptoms | Response Steps | | |
|-----------------|---|--|---|---|
| | | At Symptom Onset | If Symptoms Persist | If Symptoms Resolve |
| Mild | – Anxiety, fatigue, dizziness, or headache – Abdominal pain or nausea | – Provide rest, water, and a quiet place to recover | – Send PATIENT to the health room <u>with escort</u> | – PATIENT may rejoin class activities |
| Moderate | – Excessive sweating or shortness of breath – Chest pain or racing heart – Blue/gray coloring in lips, fingers, or feet – Vomiting, diarrhea, or fever > 100.4°F | – Send PATIENT to the health room <u>with an adult escort</u> for evaluation | – Contact parents and follow their instructions Blood-Oxygen Saturations: – May drop to XX% with exertion, but should rise to XX% after a rest break | – PATIENT may rejoin class activities Blood-Oxygen Saturations: – Readings \geq XX% are normal for PATIENT and should not raise concern |
| Elevated | – Labored breathing or wheezing – Elevated or irregular heart rate – Seizure activity | – Request health staff immediately <u>come to PATIENT</u> for evaluation – <u>Contact parents immediately</u> , and | – Follow parent/medical instructions | – PATIENT may rejoin class activities |

| | | | |
|--|---|---|--|
| Emergency | <ul style="list-style-type: none"> – Unusual decline in energy, attention, or mood – Not breathing – Irregular breathing – Gaspings/gurgling – Lack of movement – Unconsciousness – Unresponsiveness – Convulsion-like activity – Blunt blow to the chest (that causes cardiac arrest) | <ul style="list-style-type: none"> – follow their instructions – Stay with PATIENT – Call for help: have someone call 9-1-1 and contact the school’s cardiac emergency response team – Start CPR: <ul style="list-style-type: none"> A. Open Airway B. Check for Breathing C. Perform CPR – 30 chest compressions followed by 2 breaths <ul style="list-style-type: none"> ▪ Or continuous compressions if breathing is not possible ▪ Continue CPR until responsive or EMS takes over D. Use Automated External Defibrillator (AED) – turn on and follow audio/visual instructions <ul style="list-style-type: none"> ▪ AED will not deliver a shock unless necessary | |
| <p><i>*PATIENT is medically stable and emergency symptoms are not expected; appropriate response plans should be in place to manage these symptoms if they occur.</i></p> | | | |

All schools should be prepared to enact a cardiac emergency response plan (CERP), with staff trained in cardiopulmonary resuscitation (CPR) and use of an automated external defibrillator (AED). Contact CW’s Project ADAM at ProjectADAMWI@chw.org or (414) 337-1206 for **FREE** resources and support earning a “Heart Safe School” designation. To learn more about Project ADAM, visit their website: www.ProjectADAM.com.

B. Medication/Equipment Instructions & Precautions

PATIENT’s life-saving treatment regime includes medications/equipment that require special instructions and precautions.

| Medication / Equipment | Instructions & Precautions |
|---|--|
| Anti-Coagulant Medication (Coumadin, Warfarin, Aspirin) | These blood-thinner medications help prevent blood clots, but also increase risks of bleeding and bruising. <ul style="list-style-type: none"> – PATIENT should be assessed by school nursing staff for any significant bump, bruise, or cut. <ul style="list-style-type: none"> ▪ If bleeding does not stop within a reasonable amount of time with the application of firm pressure, contact parents. – Notify parents immediately following a significant blow to the head/chest to determine if further medical care is required. |
| Anti-Rejection Medication (Sirolimus, Tacrolimus) | These immunosuppressant medications are a life-long treatments for transplant recipients to prevent donor organ rejection. Some other medicines and foods counteract with anti-rejection medication and increase risks the body will reject the transplanted organ. <ul style="list-style-type: none"> – Avoid NSAIDs – non-steroidal anti-inflammatory drugs (aspirin and ibuprofen). Acetaminophen (Tylenol) is permitted. – Avoid grapefruit and pomegranate in whole fruit or juice form – risk of harmful interaction with anti-rejection medications. – Avoid live vaccines and contact with bird/cat feces, due to a suppressed immune system. |
| Continuous IV Medication via a Central Line | PATIENT requires continuous intravenous (IV) therapy of MEDICATION NAME , a medication that causes (ADD LIFE SAVING BENEFIT) . <ul style="list-style-type: none"> – This medication is continuously dispensed with a pump that must be with PATIENT at all times, through a central line catheter, which provides intravenous access for the medication. – A sterile dressing must be applied at all times at the site where the central line enters the body to prevent infection and dislodgment of the catheter. – If the central line catheter comes out at any time, immediately hold pressure at the site with gauze and call 9-1-1. Inform EMS staff about PATIENT’s medical conditions, continuous IV medication, and to take PATIENT to the nearest medical facility. – Common side effects of this medication include: (ADD SIDE EFFECTS). |
| Pacemaker | PATIENT has an implanted pacemaker device that continually monitors the heart’s rhythm and sends electrical signals to stimulate/pace the heart if its rhythm becomes too slow. The pacemaker’s electrical signal is not strong enough for PATIENT to feel. <p><u>Symptom Instructions</u></p> <ul style="list-style-type: none"> – If PATIENT becomes unresponsive, a sudden cardiac arrest should be suspected and emergency protocols should be initiated immediately: start CPR and AED therapies; place AED pads at least 1 inch away from the pacemaker. <p><u>Precautions</u> – some electronic devices may interfere with the pacemaker’s signal. PATIENT should follow these pacemaker precautions:</p> <ul style="list-style-type: none"> – Cellphones, iPads, tablets, and MP3 players must be held 6-8 inches away from the pacemaker to avoid interference. It is recommended to place a pillow on the lap to separate the electronic device the appropriate distance from the pacemaker. – Avoid high powered magnets/magnetic fields (i.e. science grade magnets and metal detectors) as they may interfere with the pacemaker. Kitchen and play magnets are safe. <i>Pacemakers are well protected from most household electrical appliances such as radios, TV’s, stereos, microwaves, computers, etc.</i> – Stand at least 2 feet away from welding equipment, high voltage transformers, and motor generating systems during Industrial Arts class or other times of exposure to this type of equipment. – Refrain from activities that may lead to a direct blow to the area of the pacemaker: no dodge ball, volleyball, tackle football, or hockey. – For fieldtrips/off-campus activities, an AED, CPR trained-responder, and an adult with a cellphone should always be available. – PATIENT should sit in the first or second seat of the bus for close monitoring. If the bus driver notices loss of consciousness, pull the bus over and immediately call 9-1-1. |
| Implanted Cardioverter Defibrillator (ICD) | PATIENT is at risk for a sudden cardiac arrest (SCA), an “electrical problem” in the heart causing the heart to stop pumping blood to the brain and vital organs. To mitigate this risk, PATIENT has an ICD device that continually monitors the heart’s rhythm and delivers a strong lifesaving electrical shock if the heart rate becomes too rapid or chaotic. This electrical shock is strong enough for PATIENT to feel and may feel like a sudden, painful kick in the chest. <p><u>Symptom/Device Instructions</u></p> <ul style="list-style-type: none"> – If PATIENT receives a shock from the ICD and recovery is immediate, notify parents and follow contact the device clinic. – If one or more shocks occur without rapid recovery, call 9-1-1. – If PATIENT becomes unresponsive, a sudden cardiac arrest should be suspected and emergency protocols should be initiated |

| | |
|--|---|
| | <p>immediately: start CPR and AED therapies; place AED pads at least 1 inch away from the ICD.</p> <p>Precautions – some electronic devices may interfere with the ICD’s signal. PATIENT should follow these ICD precautions:</p> <ul style="list-style-type: none"> – Cellphones, iPads, tablets, and MP3 players must be held 6-8 inches away from the ICD to avoid interference. It is recommended to place a pillow on the lap to separate the electronic device the appropriate distance from the ICD. – Avoid high powered magnets/magnetic fields (i.e. science grade magnets and metal detectors) as they may interfere with the ICD. Kitchen and play magnets are safe. <i>ICDs are well protected from most household electrical appliances such as radios, TV’s, stereos, microwaves, computers, etc.</i> – Stand at least 2 feet away from welding equipment, high voltage transformers, and motor generating systems during Industrial Arts class or other times of exposure to this type of equipment. – Refrain from activities that may lead to a direct blow to the area of the ICD: no dodge ball, volleyball, tackle football, or hockey. – For fieldtrips/off-campus activities, an AED, CPR trained-responder, and an adult with a cellphone should always be available. – PATIENT should sit in the first or second seat of the bus for close monitoring. If the bus driver notices loss of consciousness, pull the bus over and immediately call 9-1-1. |
| <p>Continuous Oxygen Therapy</p> <p>[USE PULMONARY /OXGEN THERAPY SYMPTOM MANAGEMENT GUIDELINES]</p> | <p>PATIENT requires oxygen therapy at all times using a portable oxygen tank or oxygen concentrator with a nasal cannula. Provide adult supervision at all times to:</p> <ul style="list-style-type: none"> – Monitor and respond to symptoms (see pulmonary symptom management guidelines below) – Provide medication when needed – Operate/check the oxygen concentrator, tank, tubing, and cannula – Ensure the oxygen tank is kept upright – Transport the oxygen tank any distance <p>Emergency Evacuations & Fire Drills – establish and practice a plan in advance of any drills/emergency, considering these precautions:</p> <ul style="list-style-type: none"> – If an oxygen concentrator is in use, PATIENT will need to transfer to an oxygen tank to exit the classroom. – Below freezing and cold air environments should be avoided – cold air decreases PATIENT’s lung functioning and may freeze the nasal cannula and/or oxygen tank, preventing oxygen delivery. – PATIENT may require an adjusted exit route and destination to accommodate oxygen tank transport and temperature restrictions. <p>Equipment Instructions</p> <ul style="list-style-type: none"> – Always keep extra oxygen tanks at school for use in the event the primary oxygen tank runs out or a power outage occurs and the oxygen concentrator cannot be used. – Store extra oxygen tanks upright in a safe and clean location, away from any direct heat sources. – Keep a few extra sets of nasal cannulas and tubing at school at all times for replacement needs. |
| Other | |

C. School Health Accommodations

The following accommodations should be included in **PATIENT**’s school health plan. If **PATIENT** already has an active school health plan, current accommodations in that plan should remain available to **him/her**.

| Health Domain | Accommodation |
|--|---|
| Health and Safety | <p>PATIENT is “immunocompromised” – his/her chronic medical conditions depress the immune system and increase susceptibility to illness.</p> <ul style="list-style-type: none"> – Encourage proper hand washing. – Sanitize frequently touched objects (desks, door handles, manipulative, etc.). – No sharing of drinks, food, snacks, etc. – Notify PATIENT’s family if a significant illness is spreading throughout the school. – Educate other students and families about the importance of informing the school or classroom teacher of any illness, so PATIENT’s family can take appropriate precautions. – Consider peer vaccine rates when assigning PATIENT’s classroom placement each year. |
| Physical Activities | <p>Self-limit activity and take breaks as needed. PATIENT may need to take breaks during physically intensive activities (i.e. during P.E. class). Following a recovery period, PATIENT should be encouraged to rejoin the activity.</p> <ul style="list-style-type: none"> – Encouraging activity is good; however, PATIENT should never be required to engage in activities that involve running or weightlifting for a grade. If s/he is not comfortable, permit alternative activities without consequence. – Inform school staff (including recess/other supervisors, substitutes, and afterschool staff) about PATIENT’s medical conditions and symptoms. Staff should remind PATIENT to take breaks if symptoms indicate a break is warranted. |
| Water and Bathroom Use | <ul style="list-style-type: none"> – Permit PATIENT to carry a water bottle at school and have unlimited access to water. Encourage him/her to sip water throughout the day. – Allow PATIENT to use the bathroom as needed. With increased fluids, it should be expected that s/he will need to use the bathroom more frequently than healthy peers. Consider developing a silent signal or pass system to keep toileting needs discrete. |
| School Absences | <ul style="list-style-type: none"> – PATIENT may have frequent medical appointments and procedures that result in school absences. With appropriate documentation, these medical absences should be excused. – Create a plan for managing absence-related class work at home to limit the amount of “catch-up work” when PATIENT returns to school. Consider using technology to support real-time remote lesson delivery, class participation, and to collect assignments. |
| Educational Achievement Partnership Program | <p>Please contact us at (414) 337-6776 to:</p> <ul style="list-style-type: none"> – Inquire about excessive or unexcused absences. – Report health concerns to PATIENT’s medical team. – Request medical documentation. – Ask questions about health and safety at school. – Ask questions about neuropsychological risks and educational planning. |

– Invite us to attend school health and/or educational planning meetings.

We would be happy to attend any school meetings in-person or via conference call as representatives of **PATIENT**'s medical care team. To alert the Children's Wisconsin team to any upcoming meetings, please use the phone number or the email address, below. Thank you for your consideration and prompt attention to this request.

Sincerely,

[ADD YOUR ELECTRONIC SIGNATURE]

[ADD YOUR NAME] **[ADD YOUR EMAIL]** **[ADD YOUR PHONE NUMBER]**

EDUCATION SPECIALIST, EDUCATIONAL ACHIEVEMENT PARTNERSHIP PROGRAM – CHILDREN'S WISCONSIN

Enclosure: School Authorization Form – **PATIENT NAME**



School Care Guidebook

Pediatric Heart Disease



Children's
Wisconsin

Educational Achievement
Partnership Program

Herma Heart Institute



This booklet is provided by the **Educational Achievement Partnership Program at Children's Wisconsin.**

The Educational Achievement Partnership Program is available to Herma Heart Institute families as a routine part of cardiac follow-up care. Our program fosters communication and collaboration between schools and hospitals for children with complex health needs, with the aim of ensuring success in educational settings.

To learn more about the Educational Achievement Partnership Program, visit childrenswi.org/eapp.



Educational Achievement
Partnership Program



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Pediatric heart disease



Pediatric heart disease is a **chronic** condition that affects heart function and the resultant circulation of blood and oxygen throughout the body. Frequently, heart abnormalities impact the amount of oxygen-rich blood that is delivered to the tissues of the body, and this includes the brain. The impact of decreased oxygen delivery to the brain helps explain why many children with heart disease also experience neurodevelopmental delays and deficits. The key areas affected include:

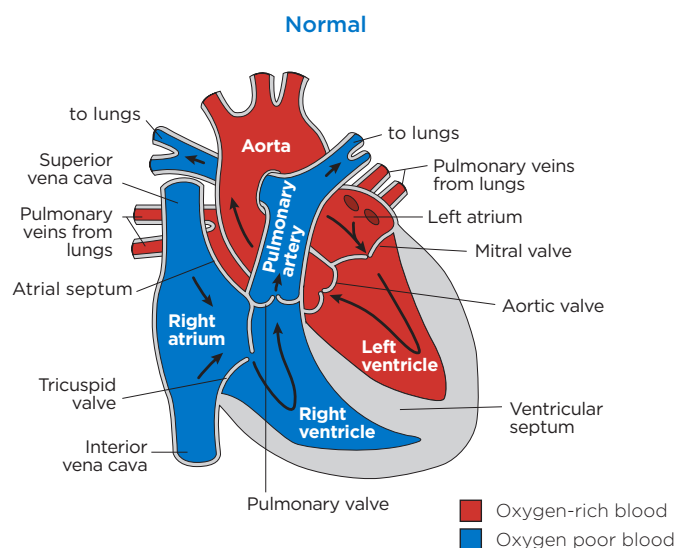
- Physical development
- Motor skills
- Language development
- Cognition
- Attention
- Behavior
- Executive functioning
- Social skills
- Emotional functioning

The management of congenital heart disease is variable and tailored to the specific diagnosis, but often involves a combination of therapies including medication, surgery, and other treatments. While manageable, pediatric heart disease and corresponding developmental impairments are never “cured”; the patient will require lifelong heart and ongoing neurodevelopmental follow-up care. In addition, these children will often require focused school support and intervention, which include school health and learning accommodations, school-based therapies, special education, and other academic supports in order to receive equal access to the same quality education experienced by their healthy peers. It is important for schools to collaborate with a child’s cardiac and neurodevelopmental care team in developing school health and education plans for these students.

Heart function

Healthy heart

The heart is a muscle that works like a pump to circulate blood through the body. While a child’s heart is about the size of his/her fist, it works just as hard as an adult’s heart, beating approximately 100,000 times each day. The four chambers and four valves of the heart are separated (two on each side) by an inner wall (septum). Veins deliver oxygen-depleted blood (blue) to the right side of the heart, which carries blood to the lungs to collect oxygen and returns blood to the left side of the heart. From there, arteries carry oxygen-rich blood (red) throughout the body.



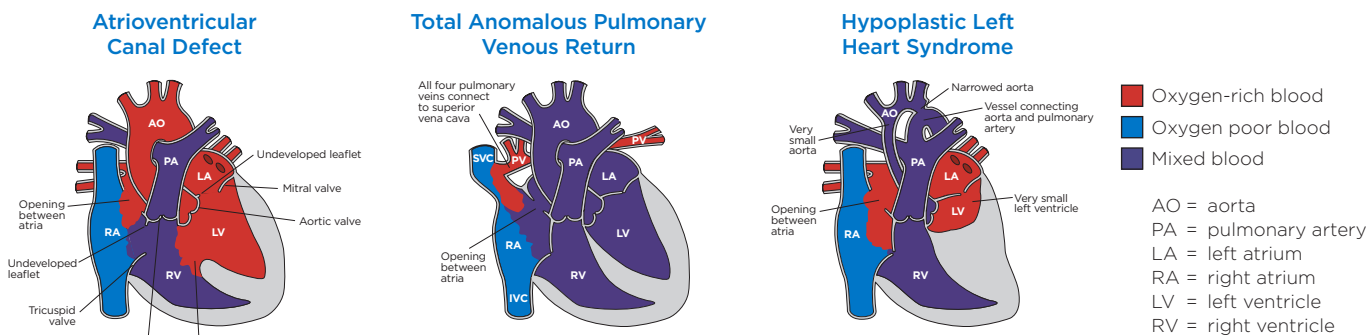
Heart disease

Heart disease can be caused by malformations, malfunctions, or viral illnesses that impair circulation and oxygen delivery to the brain and body. There are three types of pediatric heart disease: congenital heart defects (CHD), acquired heart disease, and rhythm disturbances.

CHD is the most common form of birth defect, affecting ~40,000 births (1 in 100) in the U.S. each year.

Congenital heart defects (CHD) are structural defects present at birth that develop very early in gestation. There are more than 35 types of CHD. Examples of defects include: malformed or misplaced arteries, veins, valves or chambers; holes between chambers (typically less severe – left and middle images); and the complete absence of chambers or valves (very severe – right image). CHD can be diagnosed before or after birth. Signs of heart dysfunction include: bluish skin coloring, blood pressure abnormalities, labored breathing, frequent respiratory infections, fatigue, feeding problems or poor weight gain.

Three Examples of Congenital Heart Defects and Reduced Blood-Oxygenation

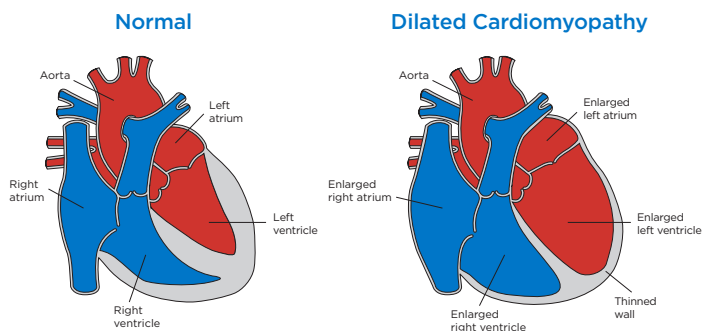


Notice how each CHD-heart is circulating "mixed blood" (purple) which is less oxygen-rich than the (red) blood circulated by the normal heart on the previous page.

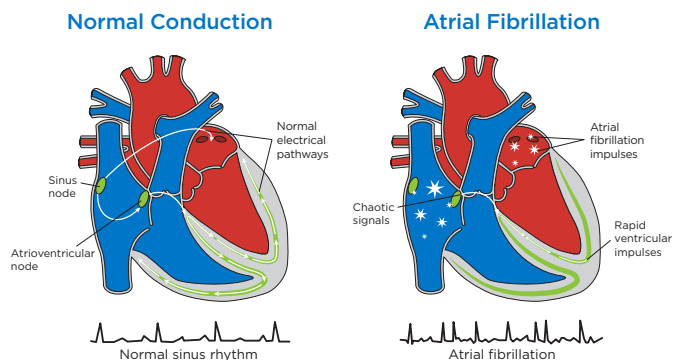
Acquired heart disease is a condition that develops after birth. These conditions can cause the heart to enlarge, weaken or malfunction, which makes the heart less able to pump blood efficiently and often leads to heart failure. Cardiomyopathy is one example of an acquired form of heart disease.

Rhythm disturbances result from disrupted electrical impulses that normally coordinate heartbeat and determine the heart's rate and rhythm. Irregularities in heartbeat, rate, or rhythm are called arrhythmias and can be congenital or acquired. Arrhythmias occur when electrical nodes within the heart misfire (as shown below).

Cardiomyopathy Heart (Enlarged)



Arrhythmia Heart (Electrical Misfiring)



Survival rates for children with congenital heart disease have improved

Source: The Emerson Rose Heart Foundation

20%
The survival rate in the 1950s

The survival rate today is more than
90%

Treatments and limitations

Due to remarkable advances in surgical techniques more than 90% of children with heart disease survive into adulthood. Most congenital and acquired heart conditions are managed with a variety of surgical and non-surgical treatment options; however, it is important to reiterate that **pediatric heart disease is a chronic condition that is never “cured” and these patients will require lifelong care.**

Notably, heart surgery often does not cure neurodevelopmental impairments, as a brain previously underdeveloped due to low oxygen commonly retains many deficits from its developmental history. Even following a successful cardiac procedure with a good medical outcome, a child will still require the **same amount or more** school support as prior to the cardiac repair. While surgical interventions and heart transplant may improve heart function, they also introduce increased risks for further complications and new or increased post-surgery developmental delays. Certain children requiring surgical intervention may undergo multiple procedures throughout their formal education lifetime; it is important to academically reassess a student following each procedure. Common examples of treatments for pediatric heart disease are included below.

A school-aged child who had heart surgery in infancy and is currently thriving from a cardiac standpoint may require a similar level of educational support as a child reintegrating to school following a recent heart surgery.

Watchful waiting

This involves active surveillance, repeat testing, and condition management aimed to allow the child to grow or heal prior to surgical intervention to increase the likelihood of operation success.

Medications

Various prescription drugs are often used to treat the different symptoms of heart disease and related conditions. Many patients require multiple medications. Some medication regimes are life-long; others can be stopped if the condition is improved. Where possible, medication times are scheduled for home dosing; however, some patients may require medications at school. Many medications have negative side effects and proper dosing requires ongoing monitoring and adjustments to prevent serious complications. Common medications used to manage heart disease include:

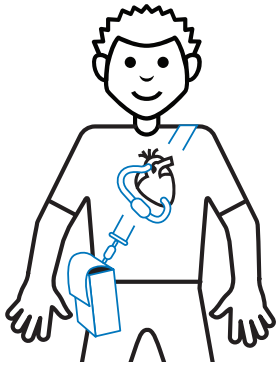


Blood thinners or anticoagulants (i.e. Coumadin or Warfarin) prevent blood clots from forming and obstructing vessels and the heart or causing stroke if they travel to the brain. Some blood thinners are very sensitive to diet. Potential negative side effects of blood thinners include increased risk for internal bleeding and bruising. Patients taking blood thinners may need to limit some types of physical activities to reduce chances of injury (especially head injuries).

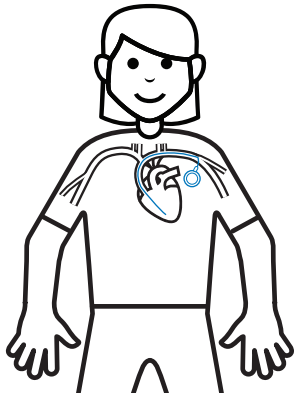
Diuretics control blood pressure but cause increased urine production and bathroom use.

Immunosuppressants prevent organ rejection following transplant but cause increased susceptibility to illness.

Mechanical assist devices – aid the heart in pumping and rhythm functions.



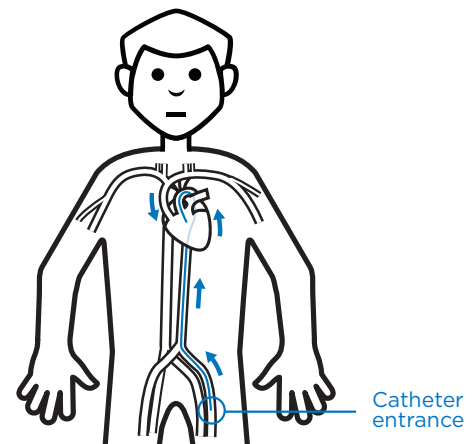
Ventricular assist device (VAD) helps pump blood when the heart is unable to work effectively on its own. This battery operated pump connects to the heart, while the controller and drivelines extend outside of the body (usually carried in a specific case, specially made shirt, or in a small backpack so the patient can move freely). This device can be used as a temporary support while patients await transplant or as a long-term support for patients who are not candidates for transplant. Some patients may attend school wearing a VAD and may require a specially trained one-on-one nursing aide to manage the VAD equipment and the patient's related care needs.



Pacemakers and implantable cardioverter defibrillators (ICD) are surgically implanted automated devices that continuously monitor and regulate heart rhythm. A pacemaker corrects minor rhythm disturbances with a series of electrical impulses (painless). An ICD counteracts more serious rhythm problems with a “cardioversion” (a small electrical shock), while life-threatening rhythms trigger a “defibrillation” (a more noticeable shock). The functions of a pacemaker and ICD may be combined into a single device. These devices may be used temporarily to regulate heart rhythm prior to surgical intervention or used as a lifelong treatment. Some students may attend school with a pacemaker or an ICD.

Catheter procedures

These procedures use small surgical tools threaded through a thin tube (catheter) that is inserted in the leg and fed through a vein to the heart. Catheter techniques allow doctors to repair some types of heart defects without opening the chest.



Open-heart surgery

In this type of operation, the chest is opened and the heart is connected to a heart-lung bypass machine, which temporarily reroutes the blood and allows for the heart to be opened and repaired. During this surgery, the bypass machine performs both the heart's pumping function and the lung's oxygenating role. While the bypass machine allows the heart to be repaired, the machine is not the equivalent of normal heart-lung function and patients experience elevated risks for seizure, stroke, and other complications while on bypass and during recovery.



Transplant

A heart transplant replaces a defective heart with a healthy donor heart. Transplant is considered a last option for patients who are not candidates for further surgical repair. Transplant recipients are at risk for organ rejection and transplant may not be a permanent solution. Additionally, transplant recipients take anti-rejection (immunosuppressant) medications that have significant negative side effects.

Common symptoms and complications

Developmental delays -

increased risk for physical, cognitive, functional, behavioral, and emotional delays and deficits

Stroke -

a disruption of blood flow and lack of oxygen to the brain causing brain cell death. Stroke may result if a blood clot forms in the heart and travels to the brain. Stroke can also result from arterial trauma during surgery

Sleep disorder -

disturbed sleep, difficulty falling asleep, or awaking during the night

Breathing disturbances -

rapid breathing, shortness of breath, difficult or labored breathing (dyspnea)

Activity intolerance -

insufficient energy (physical or psychological) to endure normal daily activities, complete required tasks, or keep up with peers

Failure to thrive -

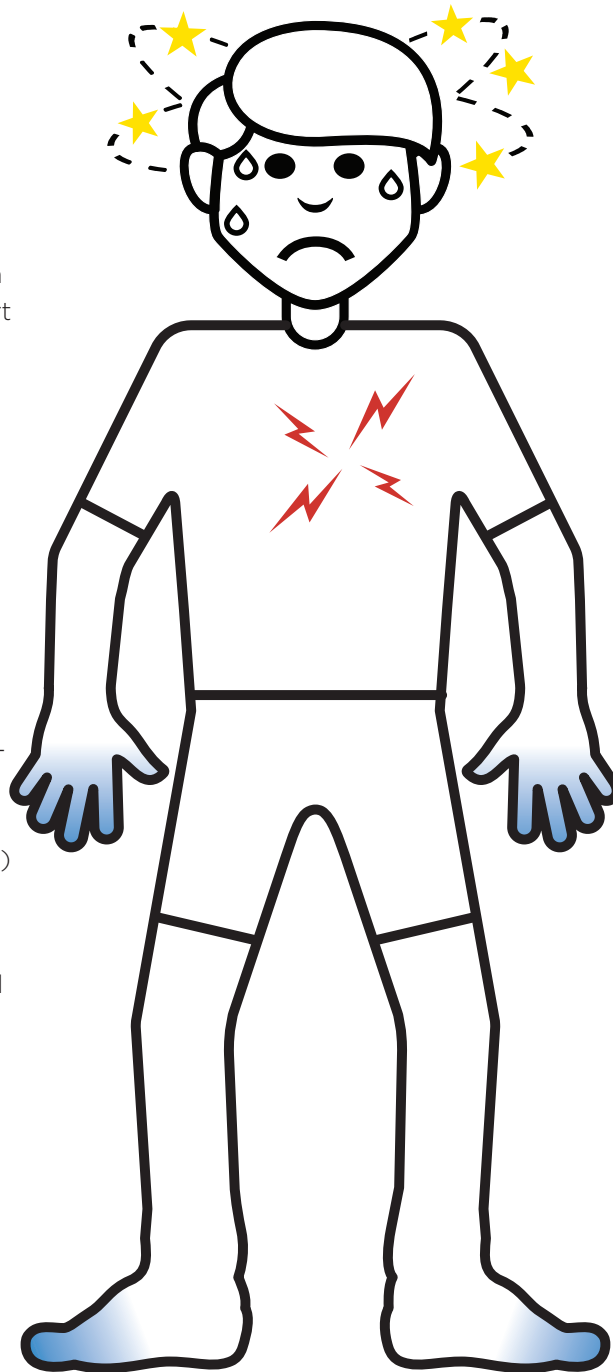
failure to gain or maintain weight

Hypoxia -

low blood-oxygen

Cyanosis -

blue/greyish coloring due to low oxygen



Syncope -

fainting

Seizure -

abnormal brain electrical activity that may result in physical convulsions, unconsciousness, thought disturbances, and other signs. Seizures may be caused by changes in heart rhythm (cardiac arrhythmia), sudden drops in blood pressure (syncopal episodes), very low blood sugar (hypoglycemia), and other triggers

Murmur -

an abnormal sound associated with blood flow through the heart

Heart rate disturbances -

heart rates that are too rapid, too slow, or erratic

Heart failure -

a heart is still functioning, but not properly

Flu-like symptoms -

weakness, fatigue, fever, chest discomfort, heart palpitations, excessive sweating, etc.

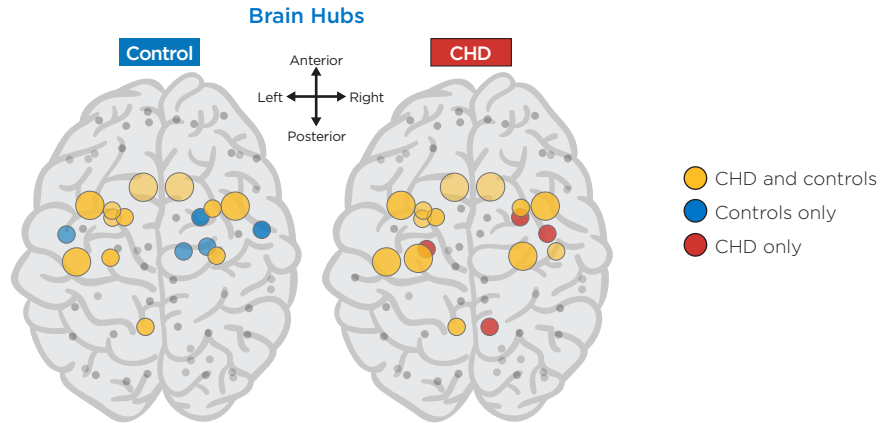
Swelling -

legs, ankles, feet, abdomen, and/or areas around eyes

Impact on brain development and function

Congenital (before birth) and acquired (after birth) heart conditions can alter blood flow, reduce blood-oxygen levels, and affect brain development and functioning. With some forms of CHD, the brain is less mature in full term infants, and is similar to the brain size / development of a premature infant.

Pediatric Heart Disease Reduces Brain Functional Connectivity

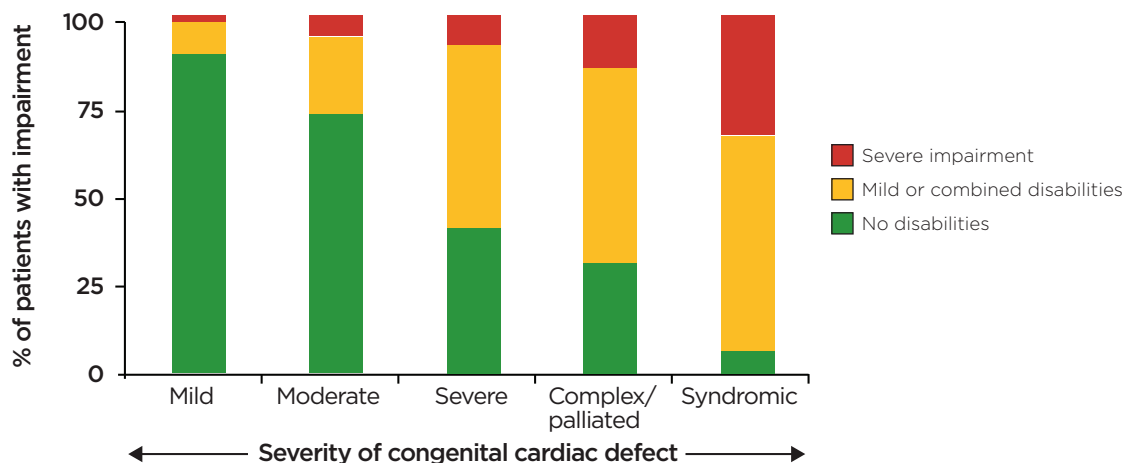


Compared to the brains of healthy newborns (control group), infants with CHD have fewer connectivity hub nodes (yellow and blue/red spheres) and reduced functional connectivity between critical brain hub regions. These connectivity disturbances affect brain regions involved in sensory information and movement control, and contribute to problems with motor function, executive function, socialization, behavior, and learning. (Adapted from De Asis-Cruz, J., Donofrio, M. T., Vezina, G., & Limperopoulos, C. (2018). Aberrant brain functional connectivity in newborns with congenital heart disease before cardiac surgery. *NeuroImage: Clinical*, 17, 31-42.)

After birth, changes in heart function, surgical treatments, other complications (seizure, stroke), long hospital stays, poor growth, and continued low blood-oxygen levels may impact brain development and functioning on an ongoing basis. Exposure to risk (surgery / complications) and the prevalence of developmental delays changes over time.

Subtle neurodevelopmental delays affecting multiple domains are extremely common and more than 50% of children with heart disease experience some form of neurodevelopmental disability.

Risk of Developmental Delays and Severity of Heart Disease

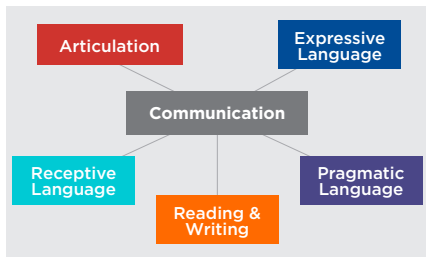


The degree of developmental delay is often associated with the severity of pediatric heart disease. (Adapted from Wernovsky, G. (2006). Current insights regarding neurological and developmental abnormalities in children and young adults with complex congenital cardiac disease. *Cardiology in the Young*, 16(S1), 92-104.)

Developmental delays affecting school performance



Physical development – feeding, growth, nutrition, toilet-training, hand-eye coordination, fine motor skills (handwriting, cutting, tying shoes), and gross motor skills (crawling, walking, running).



Language development – speech, hearing, and communication skills.



Social-emotional functioning – ability to express and manage emotions, establish and maintain friendships, and interact with adults and peers (play skills).



Executive functioning – planning, organization, independence, task management, working memory, reasoning, decision-making, mental flexibility and goal achievement.



Attention and behavior – ability to focus, stay on task, sit quietly, exercise self-control, communicate appropriately, follow directions and make transitions (change schedule).



Cognition – processing speed, academic achievement and core content acquisition (reading, writing and math).

Academic concerns

Academic concerns can arise at different developmental stages from preschool through early adulthood as independence, organization, and skill level demands increase. Children with developmental delays may require health and learning accommodations, school-based therapies (occupational, physical and speech), special education and other academic supports to achieve optimal functioning. Common subtle deficits may result in more substantial academic concerns over time if school supports are insufficient, as neurodevelopmental delays do not self-correct and these children cannot “catch up” on their own. Over time, untreated academic concerns often increase in severity while opportunities to correct poor performance decrease. Long-term challenges lead to greater academic achievement gaps negatively impacting effort, motivation, self-confidence, rigor and expectations.



Risk for Onset of ND Delays

Appearance of Academic Concerns

Opportunity to Improve School Performance

Early intervention and ongoing school supports may reduce or prevent long-term academic problems.

Since subtle academic delays are frequently missed in children with heart disease, systematic screening to identify emerging problems and early intervention may reduce or prevent long-term academic problems. It is critical for schools to work closely with hospital care teams and cardiac developmental specialists when evaluating and creating health and education plans for students with heart disease.



School health care management considerations



All students with heart disease should have an updated Individualized Health Plan (IHP) customized to the specific school health needs of that student (not based on generic emergency symptoms). IHPs for students with heart disease should consider: cardiac emergency response plans, classroom vaccination rates, medications and medical equipment, water intake and bathroom use, activity restrictions, attendance, and mobility and physiological limitations. The Children's Wisconsin cardiac follow-up care team provides IHP recommendations along with pertinent medical information and school care needs for specific patients followed by Children's Herma Heart Institute. Please contact Children's Educational Achievement Partnership Program at: **(414) 377-6776** if you have any questions about the student's medical condition and care needs or require staff medical training.

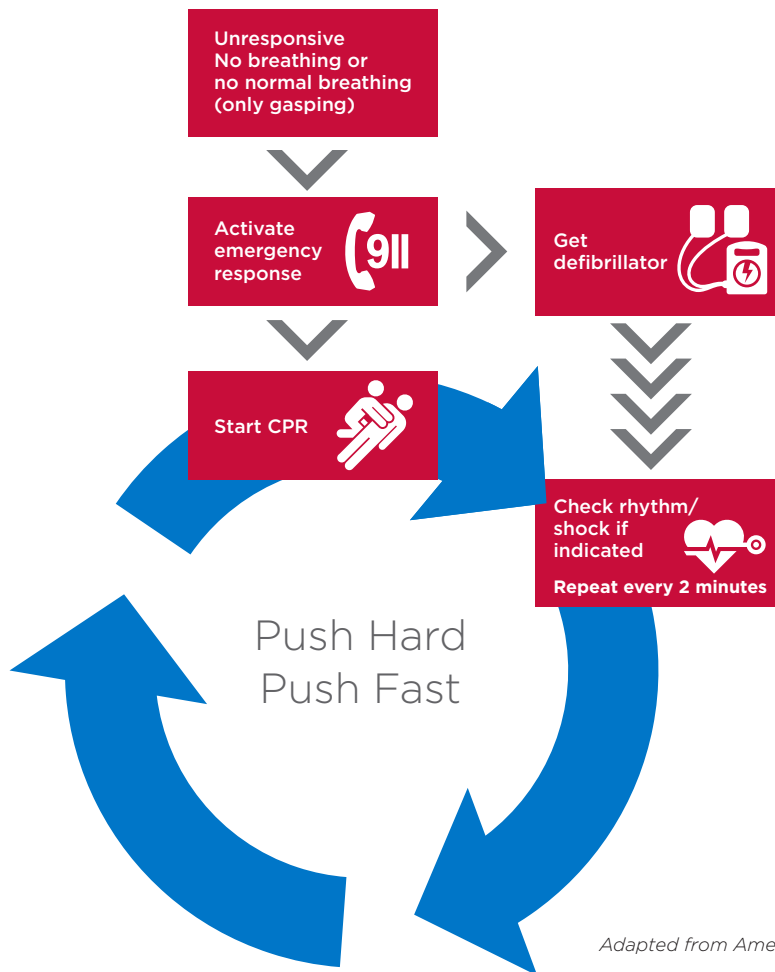
Cardiac emergency response plans

In the event of a cardiac emergency, all schools should be prepared to enact a cardiac emergency response plan (CERP), with staff trained in cardiopulmonary resuscitation (CPR) and use of an automated external defibrillator (AED). If your school needs assistance with any of these essential steps, contact Project ADAM through their website at: **childrenswi.org/projectADAM**. Project ADAM is a nationwide school outreach program founded in 1999 by Children's Wisconsin to provide schools with resources for developing and implementing CERP, CPR, and AED programs. Schools partnering with Project ADAM aim to earn a "Heart Safe School" designation by achieving the following recommendations:



1. Establish a Cardiac Emergency Response Team
2. Practice team response by running cardiac emergency drills at school
3. Implement AED placement and routine maintenance within the school (similar to fire-extinguisher protocols)
4. Disseminate the CERP throughout the school campus
5. Maintain ongoing staff training in CPR and AED use
6. Integrate local emergency medical services with the CERP
7. Review and evaluate the CERP (annually at minimum)

Cardiac Emergency Response Team Protocol



Late December of 2016, Michael collapsed while playing in a basketball game at West Allis Central High School. As an early adapter of Project ADAM, the school was able to keep Michael alive with the help of trained personnel and an on-site AED. Michael was transported by paramedics to Children's Wisconsin where he was later diagnosed with a genetic heart condition - hypertrophic cardiomyopathy - the leading cause of sudden cardiac arrest in young athletes. While Michael won't be able to play sports anymore, he's grateful to be alive and will continue to support his team from the sidelines.

Classroom vaccination rates

Federal and state regulations, with limited exceptions, require public school students to maintain vaccinations against a number of dangerous illnesses, including polio, chickenpox, hepatitis B, measles, mumps, rubella, diphtheria, whooping cough, tetanus, and HIB (Haemophilus influenza type b). Not only do these vaccines help protect that child, but they also contribute to “herd immunization” which protects children with compromised immune systems. Children with heart disease are considered immunocompromised and could become dangerously ill if exposed to diseases. Heart transplant recipients are especially susceptible to disease, as they must take immunosuppressant medications to prevent organ rejection following transplant and cannot receive some types of vaccinations.



With the increased prevalence of immunization exemptions provided for religious, cultural, and personal beliefs, classroom vaccination averages are dangerously low. The Wisconsin state classroom vaccination rates averaged less than 83% over the last few years, far short of the 92% necessary for herd immunization to be effective. It is critical for schools to monitor classroom vaccination rates and place immunocompromised students in classrooms with vaccination rates over the 92% minimum threshold to protect them from life-threatening disease.

Medications and medical equipment



Medications

Some students with heart disease may require medication administration during the school day. All medications should be brought to the school in original packaging, labeled with dosage instructions, and kept in a secure location. There should also be a set protocol for how to communicate with the child’s family when medications need to be replenished. Medications should only be administered by the school nurse or another trained staff member. All medications administered should be recorded and as-needed medication administration should be reported to the parent/guardian daily to prevent overdosing with a subsequent dose.



Medical equipment

Some students with heart disease may require medical equipment during the school day, including a wheelchair, oxygen, mechanical heart-assist device, tracheal tube-ventilator, feeding tube, hearing aids, etc. School staff that regularly interacts with a student requiring medical equipment should be properly trained on the use of the specific equipment and troubleshooting. Some students may require a part- or full-time one-on-one aide to manage medical equipment and care needs. If outside training is required, contact the child’s medical provider.

Water intake and bathroom use

Water intake

Most cardiac patients follow a daily water intake recommendation from their cardiologist, typically including unlimited access to a water bottle or other water source. Dehydration increases the complications of heart disease and often leads to hospitalization. It is important that medically recommended water intake quotas are followed throughout the day – both at home and at school. Some children may require reminders to regularly drink water to meet their daily at-school water intake quota.

Diuretic medications

Diuretic medications ease swelling and lung congestion and are commonly prescribed to patients with heart disease to make it easier for the heart to pump and control blood pressure. Diuretics rid the body of excess water and salt, increasing urine production.

Bathroom use

Increased urine production due to diuretic medication and increased water intake necessitates frequent bathroom use. Students with heart disease should be provided with unlimited or frequent bathroom access. Bathroom accommodations should consider the student's functional independence and any bathroom assistance needs.

Incontinence

As a component of gross motor delays and/or extensive hospitalization that may delay or interrupt motor skill development, some children with heart disease exhibit delayed toilet-training and/or incontinence. Bathroom use for these students may be more frequent, and should consider the student's age and occupational capabilities for independent or assisted bathroom use, following medically recommended toilet-training protocol.






Activity restrictions

Activity restrictions and self-limited activity are medically prescribed and specific to an individual student's health condition. Students with self-limited or activity restrictions should be monitored to ensure they are following these guidelines and are not overexerting themselves by trying to keep up with healthy peers.

Activity restriction examples – no running, jumping, weight bearing, contact sports; no more exertion than the equivalent of 5-10 minutes of sustained walking, etc. Specific restrictions will vary for each student.

Self-limited activity – is commonly prescribed to children with heart disease and directs the child to decide as they go if they are exerting themselves too much and need a break. Schools should monitor activity but not unnecessarily restrict activity for any child prescribed with self-limited activity. The ability to self-monitor and know when to take breaks prior to experiencing symptoms is a skill children develop as they mature. While developing these skills, some students may have special supervision requirements, such as an aide during recess or gym class.

Symptoms and school action plans – Individualized Health Plans (IHPs) for students with cardiac disease should include specific instructions when health conditions should prompt the following:

| | |
|---|--------------------------------|
|  | STAY IN CLASSROOM |
|  | IMPOSE A RECOVERY BREAK |
|  | SEND TO NURSE |
|  | CALL HOME |
|  | CALL 9-1-1 |

Attendance



Students with heart disease often require attendance accommodations for flexible or partial school day attendance and frequent absences. The child's doctor will recommend a shortened school day if the student lacks the physical or psychological stamina to endure a full school day, especially following surgery. Some students may require special bussing accommodations for partial school day attendance. Periods of homebound instruction may also be recommended if they are not medically cleared to attend school. Schools should communicate with the student's medical team to monitor medical recommendations for school attendance.

Frequent absences

Students with heart disease may be absent from school more than healthy peers due to medical appointments, hospitalization, frequent illness, and/or classroom illness. Schools should monitor absences and "blanket" or extended doctor excuses to ensure the student or parent is not taking advantage of attendance accommodations and that absences are truly medically necessary. If these absences are consistent with doctor recommendations they should always be considered "excused."

It is important for schools to communicate with the student's medical team regarding school attendance changes, as increased absenteeism may indicate a medical concern requiring follow-up with the child's doctor.

Medical appointments – Cardiac patients are closely monitored by a large team of specialists with regular clinic appointments, often requiring frequent school absences.

Hospitalization – Treatment for heart disease and its associated conditions often requires short and long-term hospitalization periods for surgeries, symptom management, illness, and other procedures.

Frequent illness – Because children with heart disease are immunocompromised and more susceptible to illness, they often experience more school absences and longer absences than healthy peers for normally common illnesses such as colds, flu and strep throat.

Classroom illness – While students are always encouraged to stay home if they are ill, this is especially critical in the classroom of a student with heart disease. With permission, classroom families should be notified that a student in their classroom has heart disease, suppressed immunity, and may require hospitalization if exposed to illnesses that do not normally threaten the well-being of healthy peers. It is important to notify the family of a student with heart disease when another child in the classroom shows signs of illness, as it may be medically recommended for a student with heart disease to stay home.



Plans for missed school work



Because most students with heart disease will experience frequent absences, schools should collaborate with parents in advance to create plans for missed instruction and homework. Such plans may include: shortened or modified assignments, utilizing different technology-based communication and educational platforms, video/audio recordings of classroom instruction, supplementary computer-based programs or apps, hospital-based instruction or in-patient tutoring, homebound instruction and partial school day attendance.

Mobility and physiological limitations

Heart disease often limits mobility, strength, vitality and alertness. Students with these limitations may require classroom accommodations such as shortened activities, modified tasks and extra assistance.



Mobility – Free and easy movement may be limited by heart disease.

Self-mobile students many need extra time to travel between classes and assistance carrying their school supplies. Students dependent on wheelchair use might need someone to push the wheelchair and special bussing accommodations for handicap accessible transportation. Students with fine motor dexterity limitations may need access to a computer, scribe, dictation, class notes or other handwriting supports. Students with gross or fine motor limitations may benefit from physical and/or occupational therapy to increase their functional mobility.



Strength – Energy, resilience, muscle power, and emotional or mental fortitude are often limited by heart disease, surgery, and hospitalization, affecting performance of typical or routine school tasks.

Students with strength limitations may require attendance accommodations, activity breaks, recovery or rest periods, and physical therapy to build strength.



Vitality – Liveliness, spirit, endurance, activity tolerance, and stamina (ability to sustain prolonged mental or physical effort) may be affected by heart disease.

Students with vitality limitations may demonstrate mental, emotional, or physical fatigue, activity intolerance, weakness, listlessness, or lack of motivation when engaging in typical school tasks. These students may be prescribed with physical therapy, activity restrictions, self-limited activity, and rest periods. Some students may also demonstrate difficulty expressing and managing emotions, maintaining attention and engaging in appropriate behaviors. Students with emotional and behavioral vitality limitations may require classroom accommodations, coping strategies and extra encouragement to consistently participate in class activities.



Alertness – Ability to maintain attention, focus, and manage environmental stimuli may be affected by heart disease. Students may have limited or heightened alertness (such as ADHD).

Students with these limitations commonly struggle to maintain alertness due to reduced stamina, energy, and decreased circulation or oxygen. ADHD is also a common neurodevelopmental consequence of heart disease and a normal side effect of many medications used to treat heart disease. Students with reduced alertness may show signs of fatigue, inability to concentrate, poor memory, lack of comprehension, etc., while students with heightened alertness may demonstrate inattention and distractibility. Students with limited alertness may benefit from rest breaks, academic scaffolding, guided task planning, and memory, processing, or comprehension supports. Additionally, students with heightened alertness may require minimized distractions, focusing cues, activity breaks, structure, organizational assistance, and pace variability.



Special education accommodations



Due to the high risk for a variety of developmental delays and impairments, students with heart disease may demonstrate adverse performance in academic and nonacademic skill development, including academic achievement, motivation, attention, behavior, communication, social-emotional functioning, adaptive behavior, classroom performance, motor skills and vocational skills. Students with heart disease demonstrate increased risk for academic delays as tasks require greater levels of skill and independence. Children without prior delays may begin to struggle as demands increase. These students may require academic accommodations through an Individualized Education Plan (IEP), Section 504 Plan, or other school support plan. Many students with heart disease and limited strength, vitality **AND/OR** alertness symptoms that adversely affect educational performance will qualify for an IEP under the Other Health Impairment (OHI) classification.

In situations of multiple delays, the child's academic evaluation should include all appropriate categories of potential impairment. In some situations, IEPs may be provided under other classifications such as Speech and Language, especially during early education when pre-academic skill assessment is limited.



Annual IEP review meetings should consider all areas of increased risk for students with heart disease and reviews should not be limited only to prior IEP services. It is not uncommon for IEP service areas to expand as the child progresses through grades.

Academic Accommodation Examples

| Curriculum | |
|--|--|
| General education | <ul style="list-style-type: none"> • Close monitoring of core academics for low-average performance • Modified or shortened assignments • Opportunities to use new concepts in multiple contexts (i.e. vocabulary) |
| Special education | <ul style="list-style-type: none"> • One-on-one core academic instruction (reading, writing, and math) • Pull-out services for supplemental instruction for below-average performance • In-class one-on-one supplemental instruction for core academics • Alternate curriculum; focus on functional and adaptive skills |
| School-based therapies | <ul style="list-style-type: none"> • Speech and language, physical therapy, and occupational therapy |
| Physical education | <ul style="list-style-type: none"> • Modified same class or separated adapted class |
| Modified curriculum | <ul style="list-style-type: none"> • Alternate textbook, lesson materials, or learning objectives |
| Modified workload | <ul style="list-style-type: none"> • Limit the amount of work sent home / time spent on homework |
| Modified testing | <ul style="list-style-type: none"> • Extra time on tests, separate room testing, oral testing, use of note sheet on tests, etc. |
| Modified grading | <ul style="list-style-type: none"> • Adapted to individual capability level or pass/fail options • Opportunities to correct errors, proof-reading assistance, not penalizing for spelling |
| Attention and Behavior | |
| Minimize distractions | <ul style="list-style-type: none"> • Seating away from audio or visual distractions; increase space between desks • Seating and proximity to teacher or among well-focused students • Allow student to use privacy boards or study carrels for testing or desk work |
| Signals and cues | <ul style="list-style-type: none"> • Verbal cues and nonverbal hand signals from teacher to stay on-task or pay attention |
| Communication | <ul style="list-style-type: none"> • Eye-contact and/or physical contact (hand on shoulder) when speaking to student • Say student's name prior to giving instructions / directions |
| Activity breaks | <ul style="list-style-type: none"> • Opportunities for controlled movement |
| Wiggle cushion or exercise ball | <ul style="list-style-type: none"> • Tool for encouraging movement while remaining seated |
| Change pace/tasks | <ul style="list-style-type: none"> • Frequently change work pace and tasks • Give shorter assignments interspersed with quiet periods |
| Consistency & structure | <ul style="list-style-type: none"> • Post daily schedule, standard seating and behavior incentive charts • Clearly define expectations, rules, and developmentally appropriate consequences; praise for effort • Incorporate student's suggestions in determining rewards and consequences • Concrete suggestions for good behavior; regular feedback / check-ins with teacher |
| Assign for success | <ul style="list-style-type: none"> • Daily tasks and classroom duties |
| Avoid frustration | <ul style="list-style-type: none"> • When teaching students with attention limitations and challenges |

Academic Accommodation Examples

| Instructional Delivery | |
|--------------------------------|--|
| Breakdown | <ul style="list-style-type: none"> Multi-component instructional and hierarchical task breakdown |
| Multi-modal instruction | <ul style="list-style-type: none"> Oral, visual, hands-on, manipulatives, demonstrations, flashcards, outlines, etc. |
| Visual aids | <ul style="list-style-type: none"> Charts, maps, pictures, timelines, and models |
| Memory supports | <ul style="list-style-type: none"> Teacher instructional repetition, student repeats instructions, mnemonics, acronyms |
| Processing supports | <ul style="list-style-type: none"> Extra time to process questions and formulate verbal responses Only call on when hand raised to ensure processed the question / prepared response |
| Comprehension supports | <ul style="list-style-type: none"> Preview pictures, pre-read questions at end of chapter, and skim section headings Highlight or use sticky notes / tabs to mark important information while reading Actively thinking about the structure of the story; self-quizzing during reading Personalize content - think about other knowledge of characters, events, or setting |
| Academic scaffolding | <ul style="list-style-type: none"> Pre-teach course material prior to class instruction (post-teach after); word wall Show examples of quality work as a model (preferably the student's own work) Help student learn to use a rubric and explain how each step will be graded Allow for a reading or study partner |
| Organization | <ul style="list-style-type: none"> Daily teacher assistance completing assignment notebook Parent access to assignments, due dates, and grades Checklists, graphic organizer, color-coded folder, help collecting homework supplies Keep student's desk clear of clutter and limit the amount of materials on desk Periodic locker organization check-ins / assistance Use graph paper or lined paper turned sideways to line up math problems |
| Guided task-planning | <ul style="list-style-type: none"> Steps and tools needed to complete tasks; breaking tasks into manageable parts Outlining assignments (essay / paragraph structure) and estimate time to complete parts Establish clear starting points, rather than just giving deadlines |
| Handwriting supports | <ul style="list-style-type: none"> Scribe, computer access, talk-to-text, audiobooks, and printed copies of class notes Training in the use of dictation software; typing / keyboarding instruction Reduced writing requirements; extra time to write |
| Social-Emotional Functioning | |
| Social cognition | <ul style="list-style-type: none"> Structured social skills training to aid in recognizing and understanding social cues |
| Minimize stressors | <ul style="list-style-type: none"> Monitor for anxiety or frustration related to school work or peer interactions Prepare new situations in advance |
| Encouragement / praise | <ul style="list-style-type: none"> Frequent and appropriate; reward good, persistent effort and desired behaviors |
| Bullying | <ul style="list-style-type: none"> Watch for signs - physical bullying is very dangerous for children with heart disease |
| Extracurricular | <ul style="list-style-type: none"> Encourage students to seek out activities of interest (plays, clubs, or sports) Options if physical limitations prevent participation (team manager, score keeper) |



Collaborating with hospital care teams



Hospital cardiac care teams are made up of a wide variety of experts, including cardiologists, surgeons, electrophysiologists, anesthesiologists, pharmacists, psychiatrists, psychologists, dietitians, therapists, social workers, and school liaisons. The integrated cardiac care team often collaborates with other hospital specialty groups (genetics, special needs, urology, renal, etc.) for patients with additional diagnoses. The hospital care team is optimally positioned to provide the most comprehensive recommendations for maintaining patient medical care at home, school, and in the community. Schools have direct access to a student's hospital care team and are strongly encouraged to use the medical team as a resource when developing health and education plans for these students, seeking school staff training, and creating cardiac emergency action plans.



The Herma Heart Institute at Children's Wisconsin is the largest pediatric cardiac program in the state and is ranked as one of the best in the nation for pediatric cardiology and heart surgery by *U.S. News & World Report*. We care for patients with congenital heart disease from before birth through adulthood, and we consistently report some of the best surgical outcomes for even the most complex types of heart disease.

But mere survival is not enough - the Herma Heart Institute is determined to see these kids thrive. In 2007, we were the first pediatric heart program in the country to offer routine developmental follow-up for patients who underwent heart surgery in the first year of life — five years before the American Heart Association and the American Academy of Pediatrics officially recommended such programs.

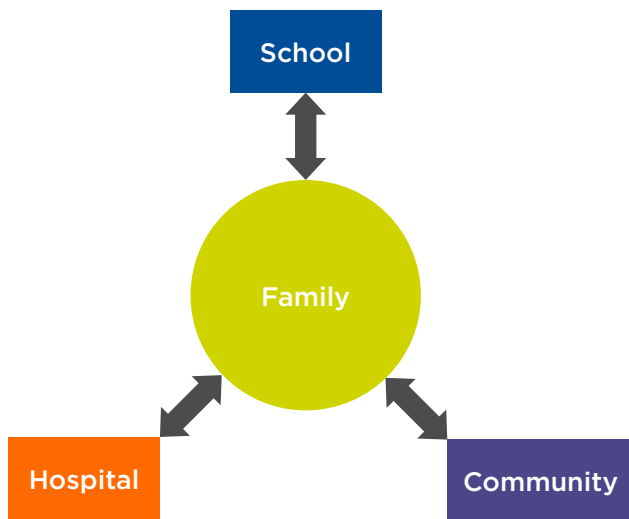
Educational Achievement Partnership Program

Despite extensive research showing significant risks for poor classroom performance in students with heart disease and related developmental impairments, structured hospital-based cardiac school intervention programs are exceptionally rare. Recognizing the school environment as a new frontier in pediatric cardiac follow-up care, Children’s Wisconsin launched the Educational Achievement Partnership Program in 2015, providing comprehensive services to school-age patients of the Herma Heart Institute. The program is led by a former educator who is specially trained in advocating for at-risk youth. This program is designed to boost academic success, motivation, attendance, attention, behavior, and social-emotional functioning by collaborating with the patient’s school to coordinate and promote strategies to manage health care and

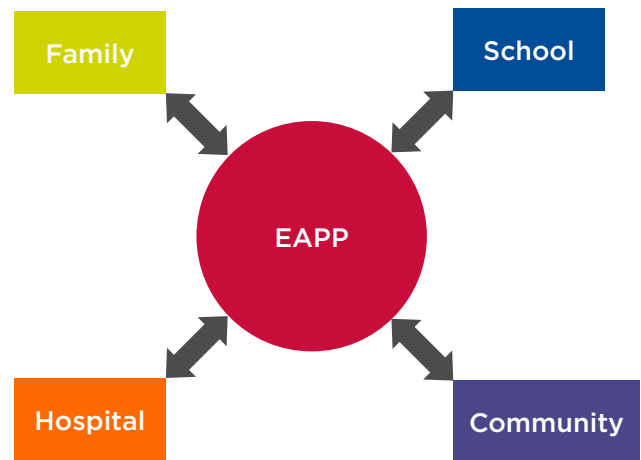
developmental impairments. The overarching objective is to optimize the use of a hospital-based school liaison who translates necessary medical information and recommendations into the language of schools, ultimately helping to set realistic academic expectations and improve overall learning opportunities.

This novel approach creates a coordinated care system with the Educational Achievement Partnership Program as the “information hub” at the center of an interdisciplinary care team, ensuring clear and consistent information for all. This strategy replaces the typical patient-centered care model which burdened patients’ families with the responsibility of communicating technical information to schools.

Typical Family-Centered Communication



EAPP Coordinated Communication System



↔ Primary medical and educational information route.

96% of students who participated in the Educational Achievement Partnership Program improved their grades, attendance, motivation, attention, behavior, and/or social-emotional functioning.

Resources for schools

The Educational Achievement Partnership Program provides schools with Individualized Health Plan (IHP) recommendations from the patient's medical providers. All students with heart disease should have an IHP incorporating information about the child's medical diagnoses, doctor recommendations for health care at school, and customized emergency action plans.

The Educational Achievement Partnership Program also provides schools with student-specific learning accommodation suggestions based on the patient's medical diagnosis, treatment history, neurodevelopmental deficits, impairments, and risk for delays. We assist schools in coordinating staff medical training and connect schools with HHI's Project ADAM affiliates to support school Cardiac Emergency Action Plans and Heart Safe School designation.

The Educational Achievement Partnership Program is available to Herma Heart Institute families to ensure success in the classroom.



To learn more, please contact:



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Educational Achievement
Partnership Program



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