

SCHOOL RESOURCE PACKET FOR TRANSPLANT FAMILIES

A COMPREHENSIVE GUIDE FOR EDUCATIONAL RESOURCES





HOW TO USE THIS RESOURCE PACKET

This packet of information was developed to assist both parents/guardians and school staff to provide continuity of care in the educational environment for students who have received organ transplants. These forms should be used as a template to guide the team and must be adjusted to reflect individual needs related to transplant care.

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Frequently Asked Questions (FAQs)

Why might my child need a 504 Plan or IEP?

Children who undergo transplantation are at an increased risk for cognitive difficulties, such as attention or learning problems, as a result of their underlying disease, transplantation, treatment, and hospitalization. When your child transitions back to school following transplantation, it will be helpful to put supports in place to help foster their success. The educational system can be difficult to navigate and obtaining services is not always easy.

What is the difference between a Section 504 Plan and an IEP?

IEPs and Section 504 Plans are written educational documents that provide accommodations to students in the school setting. For students who do not require specialized instruction but require the assurance that they will receive equal access to public education and services with their physical/mental needs being met in the general education environment, a 504 Plan is developed to outline their specific requirements. Children who have undergone transplantation can qualify for a 504 Plan based on their medical condition, and under some circumstances, such as when there are concerns about learning or cognitive functioning, may qualify for an IEP. An IEP, or Individualized Education Program, is a set of services delivered to a child that includes special education services. Students who need accommodations/modifications and specialized instruction based on a psychological evaluation will have an IEP developed.

Why is it important to have my child's needs documented in a Section 504 Plan/IEP?

Section 504 Plans and Individualized Education Programs (IEPs) are legally binding documents that hold the school district accountable for providing needed services and supports.

How do I start the process of evaluating my child's needs?

- As your child prepares to go back to school, make a request for the school evaluate your child to determine what supports he/she may need and to create or amend your child's IEP or 504 Plan. It is strongly recommended that you make this request in writing.
- Next, the school will complete an evaluation. This may include measures of cognitive functioning, academic functioning, and behavior.
- The evaluation team will schedule a meeting with you, your child's teacher, and other school personnel involved in the evaluation. The team will review the results of the evaluation and decide if your child qualifies for services. The team will decide what kinds of services are most appropriate to help your child learn. These may include: special education services, behavioral supports, or modifications to test taking or other educational activities.

What are some common accommodations/modifications needed for students who have undergone transplantation?

Children who have undergone transplantation often have difficulties with attention, focus, memory, and processing speed; this is sometimes a result of their medical condition and sometimes related to medications they take. In addition to supports recommended by the school, these are common accommodations for children with transplants:

1. Extra time on tests or tests that are untimed
2. Extended deadlines on long-term projects or modifications to the required workload
3. Various medical provisions, such as:
 - Being allowed to go to the nurse or use the bathroom when needed
 - Access to a water bottle throughout the day or a special diet
 - Modified physical education to comply with activity restrictions
 - A plan for emergency care (e.g., staff being trained to use cardiac equipment)
 - Excused absences for medical appointments
4. Your child's physician, transplant coordinator, or transplant psychologist can help you advocate for these accommodations, and can provide written documentation of medical necessity as needed.

What resources are available to provide further support for my child in the educational setting?

Many resources are available to families who have students with IEPs. A list of these resources and the student's legal rights are provided by the school district at the annual IEP meeting in a document called Procedural Safeguards. For families who have trouble getting services for their children, a special education advocate can work on behalf of the student/family to help navigate the special education process.



An Overview of School Forms for Transplant Families

Letter to School



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

Doctor Verification Letter



Purpose: Informs the school of a child's diagnosis as verified by a physician

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

Who receives it: Principal

Individual Health Plan



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 Plan*



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



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.

* While a Section 504 Education Plan may be appropriate, a student may also be eligible for an IEP. If an IEP is warranted, the sample 504 plan may be used to guide the IEP writing process to ensure that all needed physical, academic, emotional, behavioral and medical needs are being met for the student.*

LETTER TO SCHOOL

Date:

Dear Principal (Name):

My child, (Name), has received a (Type of Transplant). An organ transplant (brief description).

Although (Child's Name) may appear healthy, the ongoing effects of an organ transplant can cause sudden health changes.

(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 (his/her). It would be helpful if (Child's Name)'s teachers, the special education coordinator, school nurse, (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) has received a (type of organ transplant).

*** INSERT INFORMATION TYPICALLY USED IN THESE LETTERS FROM CLINIC STAFF/NURSE COORDINATORS/SOCIAL WORKERS.***

Sincerely,

Physician's Signature

Physician's Name

Physician Contact Information

INDIVIDUAL HEALTH PLAN

Date:

Student Information

Name:

Homeroom Teacher:

Date of Birth:

Grade:

Contact Information

Parent(s)/Guardian(s):

Father:

Address:

Home:

Work:

Cell:

Mother:

Address:

Home:

Work:

Alternative Emergency Contact:

Name:

Address:

Cell:

Physician Information

Pediatrician:

Transplant Physician:

Transplant Nurse Coordinator:

Hospital Preference:

Phone:

Health Insurance Carrier:

Health Insurance Phone:

Policy Number:

Health Condition

Diagnosis:

Description of Diagnosis:

Medical History:

Current Medications:

Frequency of Appointments:

Central Line Access & Care:

Dietary Restrictions & Feeding:

Activity Tolerance & Restrictions:

Additional Points to Consider:

Emergency Care: See detailed Emergency Plan.

SECTION 504 EDUCATION PLAN

THIS IS A SAMPLE 504 EDUCATION PLAN. INFORMATION PRESENTED HERE MAY BE USED TO DEVELOP AN IEP.

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 health care 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:

School:

Student:

Date of Birth:

Grade:

Plan Participant Names:

Title:

Parents:

Principal/LEA:

School Nurse:

School Counselor*

Regular Education Teacher:

Other:

Other:

Other:

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 organ transplants, 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:

Signs & Symptoms of Concern:

Treatment & Medical Management:

Current Medication:

Medications	Doses	Times

*Over-the-counter medications should be checked by the transplant team for compatibility with current transplant medications before being administered. NO medications should be administered without parent permission.

Medical Implications in the Educational Environment:

(Child's Name) may have frequent appointments with the transplant team. He/she may need to be excused from school for these appointments.

Because of the compromised functioning of (his/her) immune system, illnesses have a more serious effect on (child's name). Therefore, (child's name) should avoid classmates who appear sick, and parents should be notified of any infectious diseases that have been diagnosed within the classroom. All precautions should be taken to place (child's name) in a class with the highest possible vaccination rate.

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, as well as extracurricular and after-school activities:

Physical Activity:

Please note here any restrictions on physical activity and/or limitations on outside play:

- Temperature Restrictions:
- Sunscreen: For children 10 and under, please help the child apply sunscreen (provided by parent/guardian) and children over age 10 please supervise the child applying their own sunscreen.
- Hydration: The student should be permitted to drink bottled water throughout the day, especially after periods of physical activity.

Emergency Preparation:

- A copy of this Section 504 plan and Emergency Care Plan should be distributed to all teachers and substitutes that (child's name) has daily contact with.

School & Classroom:

- Letters should be sent to parents of all students in (child's name)'s grade 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 child's name uses.
- (Child's name) should receive a pass to visit the nurse between (insert times here) to take medication.
 - The school nurse should provide (child's name) with a place to rest if he/she feels fatigued or ill during the school day and parent must be notified immediately.

Other considerations:

- Keeping an extra set of textbooks at home for frequent absences and provide copies of class notes and study guides when requested.
- Encourage frequent hand-washing, especially before eating.

Academic:

- Extended time to complete assignments and tests
- Consideration should be given to providing a paraprofessional/aide to help the student manage academic/behavioral/medical needs across educational environments.
- (Child's name) should not be penalized for tardiness or absences resulting from her disease.
- Assistance given to help him/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 the parents/guardians to get these materials to (child's name) and develop a plan for making up (his/her) exams and completing her projects without penalty.
- If (child's name) is absent from school for an extended period of time (district's policy on days required for qualifying for Homebound Instruction), the Plan Coordinator should make the necessary in-home or hospital tutoring arrangements. When (child's name) returns to school, the Plan Coordinator should assist (him/her) in working with (his/her) teacher(s) to catch up with her school assignments.

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

- 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
- Plan for informing classmates about transplants (if the student consents)
- Paraprofessional/Personal Care Aide

Field Trips

- (Child's name) must have a nurse accompany (him/her) on any trips that leave school premises in order to administer medications and maintain adherence to the student's Individual Health Plan.

Animals (per CDC guidelines): The following animals are considered high-risk animals for immunocompromised people (including organ transplant patients):

- Reptiles, including lizards, snakes, and turtles.
- Baby chicks and ducklings.
- Exotic pets, including monkeys.
- Contact with these animals and their environments should be avoided by people with compromised immune systems. If you do touch these animals or their environment (their food or cage, for example), wash your hands thoroughly with running water and soap. Additionally, organ transplant patients should be extra cautious when visiting farms and when in contact with farm animals, including animals at petting zoos and fairs.

Emergency Care Plan

Date:

Name:

Homeroom Teacher:

Date of Birth:

Grade:

Medical Condition/Diagnosis:

Medication:

Allergies:

Emergency Risks:

Warning Signs & Symptoms of Serious Medical Emergency:

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
- Offer fluids/hydration if necessary
- Call parent/guardian or alternative contacts if parents/guardians are unreachable

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

- 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 – (insert staff names and phone numbers here)
- Front office to notify parent/guardian
- 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
- Inform emergency responders of preferred hospital

Family Contact Information

Relative:

Home Phone:

Work Phone:

Cell Phone:

Note: If family member is unreachable, call Transplant Team Members in order listed below.

Medical Contact Information

Medical Personnel Name:

Medical Personnel Phone:

Transplant Nurse Coordinator:

Transplant Center:

Transplant On-Call:

Pediatrician:

Hospital Preference:



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 who has received an organ transplant 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 organ transplant and related medical needs/diagnoses. Each child's plan should be created with his or her specific needs in mind and in consultation with his or her physician.

BEGINNING OF THE SCHOOL YEAR CHECKLIST

YOU KNOW YOUR CHILD BEST! YOUR CHILD'S GREATEST ADVOCATE. FOR A SUCCESSFUL SCHOOL YEAR, PLAN AHEAD AND HELP THE SCHOOL DISTRICT UNDERSTAND YOUR CHILD'S NEEDS.

- _____ Summary of Medical Diagnosis
- _____ Individual Health Plan for daily care
- _____ Medications refilled for school with required documentation
- _____ Medical supplies for school purchased and prepared (extra medication; monitoring)
- _____ Vitals; hydration; sunscreen; tube feeds; syringes; extra g-tube; central line supplies;wound care; etc.)
- _____ Dietary Plan written and filed with Food Services
- _____ Special dietary items purchased and stocked at school
- _____ Emergency Plan written and distributed to all staff
- _____ Meeting with school administration, school nurse, school counselor and teacher(s)
- _____ Related Service providers (Speech, OT, PT) aware of student's needs
- _____ Special Education paperwork: 504 Plan/IEP/Behavior Plan updated
- _____ Extracurricular/After School activity plan
- _____ Educational materials prepared to share with classmates (in coordination with teacher)
- _____ Behavior Plan: Reinforcer Checklist completed and approved
- _____ Field Trip Plans (Nursing Care; Medications; Dietary Needs; Emergency Supplies)

New School Year Parent Questionnaire

Student Name:

Grade:

Homeroom Teacher:

What safety precautions need to be in place in the classroom?

Will your child require any specific items in the classroom to help maintain medical stability? (A water bottle; a snack; etc.)

What specific health issues require a phone call home? (headache/stomach ache, etc.)

Does your child feel comfortable talking about their transplant with peers? How should I handle situations where other students ask questions about transplant/scars/care?

Briefly describe your child's past educational experiences including successes and struggles; your child's learning style and behavioral needs.

Rewards: Please list preferred and non-allowed tangible/edible items for reinforcements and classroom parties. *See attached "Reinforcement Checklist"

Ex. If the class earns a popcorn party, is this an allowable reward for your child? If not, what alternative snack could you provide? Should he/she have items such as play-doh/stickers instead of edible items.

Are there any activities that should be avoided for your child due to their medical condition?

REINFORCEMENTS

CHECK THE REINFORCERS THAT YOUR CHILD PREFERS OR ADD YOUR OWN IN THE SPACES.

Edible Reinforcers

What sweets, frozen treats, soft foods, cereals, fruits, and drinks does your child prefer?

Material Reinforcers

Does your child prefer certain material reinforcers, such as stickers, bubbles, magazines, tactile toys (like fidget spinners, squishy toys), sound-producing toys (like rattles, kazoos, zippers), or visual toys (like lava lamps, light-up toys, glow-in-the-dark toys)?

Social Reinforcers

What social reinforcers work best for your child? (You might write verbal praise, thumbs up, cheering, laughing/giggling, hugs, peer play, deep pressure, etc).

Classroom Reinforcers

What classroom reinforcers work best for your child? (You might write iPad time, free choice time, token economy, homework pass, exercise break, rest, read out-loud, sitting at the teacher's desk, lunch/snack helper, show and tell, etc).

Activity Reinforcers

What activity reinforcers work best for your child? (You might say dancing, singing, running, drawing, sand play, finger painting, dressing up, playing a game, etc).

Resources to Learn More

Websites:

- Information on special education law and resources for parents; sample letters and IEPs - www.wrightslaw.com
 - Education Law Center - www.elc-pa.org/pubs/pubs_disabilities.html
 - The Arc – Information on Special Education Policy and Advocacy - www.thearc.org
 - Center for Parent Information and Resources - <https://www.parentcenterhub.org/>
- Nationwide Special Education Toolkit Resources - <https://www.pta.org/home/family-resources/Special-Education-Toolkit/Special-Education-Toolkit-Resources>

Books:

- The Complete IEP Guide: How to Advocate for Your Special Ed Child by Lawrence M. Siegel

Each state also has a parent resource center that can provide educational advocates as needed. If you can't locate resources for your state, email StarzINetwork@gmail.com

Pennsylvania: The PEAL Center - www.pealcenter.org

The Education Law Center - <https://www.elc-pa.org/>

West Virginia: West Virginia Advocates - www.wvadvocates.org

Ohio: Disability Rights Ohio - www.disabilityrightsohio.org

New York: <http://www.p12.nysed.gov/specialed/quality/parents.htm>

Maryland: The Parents' Place of Maryland - www.ppmmd.org

Delaware: Parent Information Center of Delaware - www.picofdel.org

Arizona: Raising Special Kids - <https://raisingspecialkids.org/>



Glossary/Terms

ABA – Applied Behavior Analysis	IEP – Individualized Education Program
ABC – Antecedent, Behavior, Consequence	IFSP – Individualized Family Service Plan
ADA – Americans with Disabilities Act	IQ – Intelligence Quotient
ADD – Attention Deficit Disorder	ITP – Individualized Transition Plan
ADHD – Attention Deficit Hyperactivity Disorder	LEA – Local Education Agency
APS – Approved Private School	LEP – Limited English Proficient
ASD – Autism Spectrum Disorder	LRE – Least Restrictive Environment
ASL – American Sign Language	MA – Medical Assistance, Medicaid
AT – Assistive Technology	MDE – Multidisciplinary Evaluation
AYP – Adequate Yearly Progress	ODD – Oppositional Defiant Disorder
ACC – Augmentative Communication	OHI – Other Health Impairment
BCBA – Board Certified Behavior Analyst	OT – Occupational Therapy
BIP – Behavior Intervention Plan	PBSP – Positive Behavior Support Plan
CDC – Centers for Disease Control and Prevention	PDD – Pervasive Developmental Disorder
DD – Developmental Delay	PP – Paraprofessional
DI – Direct Instruction	PT – Physical Therapy
ED – Emotional Disturbance	PTE – Permission To Evaluation
EI – Early Intervention	PTRE – Permission to Reevaluate
ELL – English Language Learner	RR – Reevaluation Report
ESL – English as a Second Language	RS – Related Services
ER – Evaluation Report	RTI – Response to Intervention
ESY – Extended School Year	SAS – Supplementary Aides and Services
FAPE – Free and Appropriate Education	SLD – Specific Learning Disability
FBA – Functional Behavior Assessment	SLP – Speech-Language Pathology
FERPA – Federal Educational Rights and Privacy Act	SSI – Supplemental Security Income
ID – Intellectual Disability	TSS – Therapeutic Staff Support
IDEA – Individuals with Disabilities Education Act	VB – Verbal Behavior
IEE – Independent Education Evaluation	VR – Vocational Rehabilitation