# TABLE OF CONTENTS

- My Treatment Summary ........................................... 3
- General Information ............................................. 5
- Who to Call: Important Phone Numbers ...................... 7
- When to Call ......................................................... 9
- Your Healthcare Team at CHOP ............................... 12
- Oncology Clinic Visits ........................................... 14
- Transportation & Parking ......................................... 17
- Food Options ....................................................... 19
- Lodging ............................................................... 22
- Other Patient and Family Resources ......................... 24
- Support Services .................................................. 24
- Help with Financial Matters .................................... 26
- Cancer Resources ................................................ 29

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MY TREATMENT SUMMARY

Name: ____________________________________________

Diagnosis: ___________________________________________

My treatment will likely include:

☐ Chemotherapy (medicine that gets rid of cancer cells)
☐ Surgery (taking the tumor/cancer cells out with an operation)
☐ Radiation therapy (high-energy beams to kill cancer cells)
☐ Immunotherapy (medicine that helps the immune system destroy cancer cells)

My treatment will take place:

☐ In the outpatient clinic
☐ In the Hospital
☐ Both in the Hospital and in the outpatient clinic

My treatment will start: _________________________________

My treatment will last: _________________________________

My team includes:

Primary Oncologist: ___________________________________
Nurse Practitioner: ___________________________________
Nurse Navigator: _______________________________________
Social Worker: _________________________________________
Child Life Specialists: _________________________________
Other: _______________________________________________
Other: _______________________________________________

How to contact my healthcare team:

Daytime: _____________________________________________
After hours: ___________________________________________
Home care company: ___________________________________
Other: _______________________________________________

Adapted from Children’s Hospital of Wisconsin
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GENERAL INFORMATION
GENERAL INFORMATION

We know that this is an overwhelming time for you and your family. You are getting a lot of information and you will have many questions. Your oncology healthcare team at Children’s Hospital of Philadelphia (CHOP) is here to support you.

While you are in the Hospital and in clinic, your nurses will teach you about your child’s care. You will have the opportunity to attend our Oncology Home Management Class to learn about your child’s care. The healthcare team will have many discussions with you as well. Always feel free to ask any member of the healthcare team your questions. You may even have to ask the same question a number of times, as you start to learn this new information, and that is OK!

Patients and families will meet with an Oncology clinical pharmacist before discharge from the inpatient unit for a Medication Counseling session. The pharmacist will review all of the medications your child will take at home.

Before you leave the Hospital, we encourage you to watch a video about the clinic where your child will receive follow-up treatment to learn more about what to expect at clinic visits. If you will follow up at the Buerger Center, a member of the clinic staff can also bring you to the outpatient oncology clinic for a tour. Talk to your inpatient nurse about setting up a tour.

Buerger Center clinic video:
Search “CHOP, Buerger Center” on YouTube or go to bit.ly/oncobuerger

King of Prussia, Pa., clinic video:
Search “CHOP, King of Prussia” on YouTube or go to bit.ly/oncokop

Voorhees, N.J., clinic video:
Search “CHOP, Voorhees” on YouTube or go to bit.ly/oncovnj

After your child’s diagnosis, you will have the opportunity to talk about financial questions you may have with the Oncology financial liaison. See Page 26 for more information.
WHO TO CALL: IMPORTANT PHONE NUMBERS
WHO TO CALL: IMPORTANT PHONE NUMBERS

Your questions are important to us! Please call with questions about your child’s care or with any concerns you may have while you are at home:

DAYTIME HOURS:
If you are a patient of the Buerger Center Oncology Clinic, call:
Phone Nurse, 215-590-2299 (Press 6)
The phone nurse is available from 8:30 a.m. to 5 p.m., seven days a week, including holidays.
You can also call the Phone Nurse line for:
• Prescription refills (Press 3)
  You may call and leave a message with information about your request. The prescription messages are reviewed every day. Please note that some prescriptions may take several days to process.
  Please try to give at least one week’s notice.
• Scan/test results (Press 4)
• Insurance questions (Press 5)

If you are a patient of the King of Prussia (KOP) Oncology Clinic, call:
KOP Nurse, 267-425-8800 (Press 6)
KOP nurses are available from 8 a.m. to 4:30 p.m., Monday – Friday.
On weekends, call the Buerger Center Phone Nurse, 215-590-2299, from 8:30 a.m. to 5 p.m.

If you are a patient of the Voorhees (VNJ) Oncology Clinic, call:
VNJ Nurse, 856-435-7502,
VNJ nurses are available from 8 a.m. to 4:30 p.m., Monday – Friday.
On weekends, call the Buerger Center Phone Nurse, 215-590-2299, from 8:30 a.m. to 5 p.m.

FOR ALL ONCOLOGY PATIENTS, AFTER 5 P.M.
Please call 215-590-1000 (Main Hospital) and ask for the Oncology Fellow on call.
The Hospital operator will page the fellow, who will return your call as quickly as possible.
If you have not received a return call after 15 minutes, please call the Main Hospital number again.
Please make sure your phone accepts calls from a blocked caller so the fellow is able to call you back.
If you do not receive a call back and your child has a fever or does not look well, please go to the closest Emergency Room.

To schedule clinic appointments and tests:
Oncology Clinic at the Buerger Center: 215-590-3025
Oncology Clinic at KOP: 267-425-8800
Oncology Clinic at VNJ: 856-435-7502

Inpatient Units: 215-590-5538 (3 South), 215-590-2682 (3 East)
WHEN TO CALL
WHEN TO CALL

CALL 911 RIGHT AWAY IF YOUR CHILD:

- Is not breathing or is having difficulty breathing
- Has skin and lips that look blue
- Has change in behavior or level of consciousness: is not able to wake up (loss of consciousness), or not making sense when talking
- Is having a seizure and you have not been taught what to do for seizures at home

CALL YOUR CHOP ONCOLOGY TEAM RIGHT AWAY (DO NOT WAIT UNTIL THE CLINIC OPENS) IF YOUR CHILD HAS:

- Fever: **Fever in a child with cancer can be an emergency.** Call CHOP immediately if your child has a temperature of:
  - 101.3 F (38.5 C) or higher, even once in a day OR
  - 100.4 to 101.2 F (38 – 38.4 C) 3 times in 24 hours (taken at least 2 hours apart)
- Chills/shivering
- Trouble breathing
- Bleeding that does not stop within 5 to 10 minutes
- Is not making sense when talking, or is very sleepy
- Sudden change in vision
- Severe headache or repeated headache
- New weakness of the face, arm or leg
- Severe or new pain
- A break in the central line
- Continued vomiting or diarrhea
- Not been able to drink fluids
- Been exposed to chickenpox or shingles

**Important information about fever:**

- Make sure you have a thermometer at home that works. Your nurses can give you a thermometer if you need one.
- You do not need to check your child’s temperature every day. Take the temperature if your child feels warm to touch or does not look or feel well.
- Never check a temperature rectally. Oral (under the tongue) and axillary (under the arm) are the best options for checking a temperature.
- Write down the temperature and the time that you took it.
- Always call first! Do NOT give acetaminophen (Tylenol) for a fever unless the oncology team tells you to.
- NEVER give aspirin or ibuprofen (Advil, Motrin) or naproxen (Aleve).
- Give lots of clear liquids to drink.
- You will be directed to come to clinic or go to the closest Emergency Room (ER). Bring your **CHOP Emergency Room Card** with you.
  - You may want to make a “fever bag” that is packed with items you may need for an unexpected clinic or ER visit to include: change of clothes, underwear/diapers, snacks/drinks, your child’s comfort item, any supplies needed for your child’s care.

*continued >*
WHEN TO CALL continued

OTHER REASONS TO CALL THE CHOP ONCOLOGY TEAM:

• Signs of infection to call for:
  • Pain, redness or swelling anywhere in the body
  • Sore throat
  • Pain when urinating or having a bowel movement

• Signs of bleeding to call for:
  • Blood in the urine or stool
  • Vomit or stool that looks black
  • Easy bruising or tiny, red freckles on the skin (petechiae)

• Gastrointestinal side effects to call for:
  • Nausea/vomiting: You may have medicines to give at home to help with nausea and vomiting. If the medicines are not working, call CHOP’s Oncology team. Offer small meals/snacks and encourage liquids.
  • Diarrhea: if your child has 5 or more loose bowel movements in 24 hours
  • Dehydration: if your child is not drinking enough liquids to urinate 5 or 6 times a day/making wet diapers, or if their urine is dark. Other late signs of dehydration include crying without tears and dry skin/lips/mouth.
  • Constipation: if your child has not had a bowel movement in 2 or more days, is having hard bowel movements, difficulty passing stool and/or pain

• Signs of pain to call for:
  • If pain is new, or if pain does not get better with pain medications your child has been prescribed
    • Whenever giving Tylenol for minor pain, always check a temperature first! You do not want to cover up a fever. If your child does not have a fever, it is OK to give Tylenol. If your child does have a fever, call the Oncology team immediately!

• Problems with the central line to call for:
  • Chills with flushing
  • Swelling, pain or redness around the central line site
  • Drainage (pus) at the central line site
    • Call your Home Care company if:
      – Flushing is difficult
      – Dressing or caps need to be changed or have come off
YOUR HEALTHCARE TEAM AT CHOP
YOUR HEALTHCARE TEAM AT CHOP

The Children’s Oncology Group (COG) Family Handbook that you received in your binder describes many members of the healthcare team that are common to all hospitals and outpatient clinics (Pages 3-5). These members include: attending physicians, oncology fellows, nurses, nurse practitioners, child life specialists, chaplains, dietitians, pharmacists, physical/occupational/speech therapists, social workers and school teachers.

The CHOP Oncology team also includes the following people:

Art and Music Therapists – Trained professionals seeking to bring positive changes for children and adolescents with cancer. Participation in art and music therapy provides patients with ways to express themselves that may not be possible through other activities.

Case Manager – A nurse who coordinates home care needs between the family, the healthcare team and the insurance company.

Patient-Family Education Specialist – An advanced practice nurse who has both pediatric oncology and education experience and makes sure that all families receive the medical information needed to safely care for their child at home.

Oncology Financial Liaison – A person who works with you and your insurance company to confirm your insurance eligibility and to determine insurance benefits. You will meet the financial liaison within the first month after your child’s diagnosis. She will guide you as you learn about your financial responsibility and is a resource for your health insurance needs.

Nurse Navigator – A nurse with pediatric oncology experience who helps coordinate patient care, serves as a consistent contact for patients/families and communicates with all members of the team about your child’s care.

Patient Resource Navigator – A social worker, funded by the American Cancer Society, who supports families and the psychosocial team by making referrals to resources at CHOP and outside organizations.
ONCOLOGY CLINIC VISITS
ONCOLOGY CLINIC VISITS

The oncology clinic (Buerger Center, KOP or VNJ) is where your child will see the physician or nurse practitioner when not in the Hospital. There will always be a team of nurses working with your child, and you will stop at a number of places during your clinic visit:

Registration Desk:
• When you arrive in the oncology clinic, you will stop at the registration desk. Please make every effort to be sure you leave enough time to park and get to your appointment on time.
• Please make sure to have a referral if required by your health insurance plan.
• Your child will receive an ID band. Please alert the staff if your child has been exposed to chicken pox or shingles, has a rash or has recently been on isolation precautions on the inpatient unit.
• For Buerger Center patients, the parking ticket can be validated at the Registration Desk. There is no parking fee at KOP or VNJ.

Triage:
After registration, your child will be called to the triage area. This is where clinic staff will check your child’s height and weight and vital signs (blood pressure, heart rate, breathing rate, temperature). You will be asked about your child’s allergies and an allergy band will be placed if needed.

Vascular Access Rooms/Phlebotomy Lab:
If your child needs a dressing change, port access, peripheral IV placement and/or labs drawn from a central line, your nurse will call you to a vascular access room. There is also a phlebotomy lab in all oncology clinic locations for children who need labs and do not have a central line.

Exam Rooms:
Visits with your child’s physician/nurse practitioner will take place in an exam room. Your child will be examined and your child’s care will be discussed. Always bring a current list of your child’s medications, including any supplements, and request prescription refills during your appointment.

Day Hospital: Patients are seen here for:
• Outpatient chemotherapy
• Blood and platelet transfusions
• Chemotherapy admission: If your child is being admitted to the inpatient unit for chemotherapy, it may be started in the Day Hospital before your child is transferred to the Main Building. Our goal is to start chemotherapy as soon as it is available in the clinic. Your child will then be transferred to the inpatient unit when there is a bed available.
• Recovery after procedures with anesthesia: If your child has a procedure with anesthesia in clinic (such as a spinal tap/lumbar puncture, bone marrow aspirate or bone marrow biopsy), they will be brought to the Day Hospital after the procedure, where a nurse will monitor them as they wake up from the sedation/anesthesia medications.
• Sick visits: Always call the Phone Nurse/Fellow on Call if your child is sick. Sick patients will be seen in clinic Monday – Friday, 8:30 a.m. to 4 p.m. If your child is sick, he may be taken to the Day Hospital for IV medications or fluids. If it is a weekend, or after 4 p.m., you will be directed to take your child the CHOP Emergency Room. If you live more than one hour from CHOP, you may be directed to the closest Emergency Room.

Playrooms:
There are playrooms and teen spaces (for patients over age 13) in the clinic and Day Hospital. Child life specialists, art therapists, music therapists and volunteers spend time in these rooms in structured play activities for patients.
ONCOLOGY CLINIC VISITS

Nourishment Rooms:
There are rooms stocked with snacks and drinks located in each oncology clinic.

Family Resource Lounge:
This lounge in the Buerger Center clinic has a TV, computers/printer, charging station and kitchen.

Checkout:
After your visit ends, always stop at one of the Checkout Desks to schedule your next appointment.

Please remember that a responsible adult must be with your child at all times during the clinic visit, and that children should not be left alone.

WHAT TO BRING
Sometimes clinic visits can be longer than expected. The following are a few suggestions of things to bring:

- List of current medications
- List of medication refills needed
- List of questions for the oncology team
- Results of labs/scans completed outside of CHOP
- Your child's preferred snacks, drinks for longer clinic days
- Your child’s comfort item/favorite toy
- Change of clothes, diapers, underwear
- Entertainment to pass the time: tablets/devices, DVDs/Playstation games (each chair in the Day Hospital has a DVD/Playstation console and many movie/game options), books, magazines. CHOP has free Wi-Fi.
TRANSPORTATION AND PARKING
TRANSPORTATION AND PARKING

Call 215-590-7275 or visit chop.edu/directions for directions to CHOP’s Main Campus and outpatient locations by car or public transportation.

Discount parking is available at CHOP’s Main Campus locations. Please bring your parking ticket to any patient information desk or registration desk in the Hospital or Buerger Center for validation.

Main Building
3401 Civic Center Blvd., Philadelphia, PA 19104
The Main Building Garage is open 24 hours for families and visitors of patients in the Hospital. Elevators connect the garage to the Hospital.

Richard D. Wood Pediatric Ambulatory Care Center
Osler Circle, Philadelphia, PA 19104
The Wood Garage is open 24 hours for families and visitors of patients in the Hospital. Elevators connect the garage to the Hospital, and a walkway connects the second floor of the Wood Center to the third floor of the Main Building.

Buerger Center for Advanced Medicine
3500 Civic Center Blvd., Philadelphia, PA 19104
The Buerger Center Garage is open from 7 a.m. to 8 p.m. for patients and families with outpatient appointments. Take the parking garage elevators to the first floor. Stop at the Welcome Desk for a visitor’s pass. Take the lobby elevators to the third floor, Oncology Clinic.

Specialty Care and Surgery Center, King of Prussia, PA
550 South Goddard Blvd., King of Prussia, PA 19406 (next to the Wegman’s Shopping Center)
Free parking is available directly in front of the building. The Oncology Clinic is on the second floor.

Specialty Care and Surgery Center, Voorhees, NJ
1012 Laurel Oak Road, Laurel Oak Corporate Center, Voorhees, NJ 08043
Free parking is available directly in front of the building.

Ruth and Raymond Perelman Center for Advanced Medicine
3400 Civic Center Blvd., Philadelphia, PA 19104
If your child receives radiation at the Perelman Center, free valet parking and free garage parking are provided during treatment visits. Your parking ticket must be validated at the Registration Desk in the Radiation Department.
FOOD OPTIONS
**FOOD OPTIONS**

**Room Service**
Room Service is available for patients admitted to the Hospital between 6:30 a.m. and 8 p.m. Call 4-FOOD to place your order, and within 45 minutes, your food will be at your bedside. Family members can also call in an order from home, if your child isn’t old enough to do it themselves. If you are outside CHOP, call 215-590-3663.

Guests and parents can also order from the Room Service menu. There is a $5 charge for any meal, which you must pay for with a voucher, available at the CHOP Gift Shop. If you don’t want to leave the bedside, you can order a voucher by phone (267-426-9240) or at www.chopgift.com (search for “meal”). Vouchers are delivered to patient rooms periodically through the day.

**Food Storage**
The oncology inpatient units and outpatient clinics have refrigerators for food storage. All foods must be labeled with a name and date.

**Main Building Food Court**
The Food Court is located on the first floor of the Main Building. Gift cards to the cafeteria can be purchased at the CHOP Gift Shop and online at [www.chopgift.com](http://www.chopgift.com).

**Hours of operation:**
- 6:30 a.m. to 10:30 a.m.
- 11 a.m. to 3:30 p.m.
- 4 p.m. to 7:30 p.m.
- 1 a.m. to 4 a.m.

*continued*
FOOD OPTIONS continued

Coffee Carts
Dr. Coffee, located across from the Food Court in the Main Building, serves specialty coffees, tea, snacks and sweet treats, open 24 hours, Monday – Friday; 6 a.m. to 7:30 p.m. on weekends.

Coffee Carts are also located at the Specialty Care Centers at King of Prussia and Voorhees.

Buerger Center Café
Located on the first floor of the Buerger Center, with indoor and outdoor seating, and an Einstein Bagels. Open Monday – Friday, 6:30 a.m. to 4 p.m.

Vending Machines
Vending machines located in the Main Building:
• Food Court
• Near the elevators on sixth and eighth floors
• Next to the Emergency Room.

There are also vending machines in the waiting areas of the oncology clinic at the Buerger Center and at the KOP and VNJ oncology clinics.

Gift Shop/Convenience Stores
Main Building: First floor
• Open Monday – Friday, 7 a.m. to 1 a.m., and weekends from 9 a.m. to 1 a.m.

Buerger Center: First floor across from Einstein Bagels
• Grab and Go: open Monday – Friday, 6:30 a.m. to 4:30 p.m.

Wood Building: First floor, under stairs
• 3C Shop open Monday – Friday, 6:30 a.m. to 5 p.m.

Restaurants near CHOP’s Main Campus:
Au Bon Pain: Serves coffee, salad, soups, sandwiches and fresh baked goods. Located across Osler Circle from the Wood Building, next to the Abramson Research Building.

Starbucks: Coffeehouse located in the Perlman Center for Advanced Medicine, next to the Buerger Center and across from the Emergency Room.

Jimmy John’s Sandwiches: Gourmet sandwich shop in the Perlman Center for Advanced Medicine, next to the Buerger Center and across from the Emergency Room.

Kitchen Gia: Casual Italian cafe serving specialty coffee and tea drinks, breakfast dishes, pizza, soup, and salads and sandwiches. Located in the Perlman Center for Advanced Medicine, next to the Buerger Center and across from the Emergency Room.

Additional resources for local food and restaurants are available on the inpatient units, in the Center for Families near the Main Building entrance and in the Connelly Resource Center (eighth floor, Main Building).
LODGING
LODGING

In-room
Each patient room is equipped with a couch that can be used as a bed for one caregiver. Two caregivers are allowed to sleep at the bedside, but a sleep surface is only provided for one. Caregivers can bring an additional air mattress for a second caregiver. It must be put away by 8 a.m.

Parent Sleep Rooms
There are a limited number of sleep rooms in the Connelly Resource Center for Families, as well as other areas of the Hospital, that are available to inpatient families. Priority is typically given to intensive care unit (ICU) families. Distance from home is also considered. Stop by the Connelly Center or ask your social worker for assistance in requesting a room. Requests must be submitted by noon on the day the room is needed.

The Ronald McDonald House (Philadelphia and Camden, N.J.)
A place to stay at night for families that travel long distances for treatment. The room charge is $15 per night (rate subject to change). Talk to your social worker for more information.
- Ronald McDonald House Philadelphia: 3925 Chestnut St., 215-387-8406
- Ronald McDonald House Camden: 550 Mickle Blvd., 856-966-4663

Hosts for Hospitals
Lodging and support at volunteer-host homes to patients and their families who come to the Greater Philadelphia area for specialized medical care.
Call 215-472-3801 or visit www.hostsforhospitals.org for more information.

Chai House Philadelphia
3434 Sansom St., 1-877-CHAI LIFE
The Chai House is a place for children and their families to stay while undergoing treatment. Call and ask to speak with the social worker.

Sheraton University City Hotel
3549 Chestnut St., 215-387-8000
A select number of rooms offered at a discounted CHOP rate are available for families of patients being treated at CHOP, as well as those referred from the Ronald McDonald Houses when they are full.

Homewood Suites:
4109 Walnut St., 215-382-1111
Local hotel that offers shuttle service to/from CHOP.

AKA University City
2929 Walnut St., 215-372-9000
Apartment style living for families that anticipate having an extended stay in the Philadelphia area.

Art Museum Guest Houses

Additional information can be found on CHOP's website: chop.edu/patients-and-visitors/resources/where-stay
OTHER PATIENT AND FAMILY SUPPORT SERVICES
OTHER PATIENT AND FAMILY SUPPORT SERVICES

Ronald McDonald Room
(for inpatient families)
The Ronald McDonald Room, located on the 3 South inpatient unit, provides families with a cozy environment where they can meet each other, watch television, eat meals and store food in the kitchenette. Activities such as haircuts, massages and parent dinners are often held here. Laundry facilities for oncology patients and families are available here. Laundry soap is provided.

The Connelly Resource Center for Families
The Connelly Center, located on the eighth floor of the Main Building, is a place to support patients, parents, caregivers, siblings and other relatives. The Center consists of:

- The Hospitality Area
  The Hospitality Area welcomes families 24 hours a day, seven days a week. The following services are always available for families:
  • Laundry facilities
  • Kitchen area
  • Lactation room
  • Informational brochures
  • Hotel-lobby-like area to relax

- The Family Library
  The Family Library is a regular library where families can borrow books, DVDs and PlayStation games. The library hours are:
  • Monday through Thursday, 10 a.m. to 9 p.m.
  • Friday, 10 a.m. to 6 p.m.
  • Saturday and Sunday, 10 a.m. to 5 p.m.

- The Family Learning Center
  The Family Learning Center offers classes in a quiet environment. Caregivers can learn the skills necessary to care for their child’s healthcare needs at home.

Please call 215-590-4968 for more information.

Spiritual Care
An oncology staff chaplain works full-time providing spiritual care and support according to each family’s needs. Families may want to pray, have their child baptized or participate in the weekly “Spirituality Group” on Wednesday evenings (held on the inpatient oncology unit). Talk to your nurse or social worker if you would like to speak with the oncology chaplain.

- The Schlimm Center for Prayer and Reflection
  is a non-denominational chapel on the first floor of the Hospital. It is open 24 hours a day for prayer and meditation. The Schlimm Center holds a weekly interfaith service every Sunday. In addition, a priest and lay Eucharistic ministers are available to Catholic patients on Sundays. The chaplain can also arrange to have a Rabbi or Imam come to meet with families. An on-call chaplain is always available to be paged on nights and weekends.

The Center for Families
The new Center for Families, across from the Welcome Desk at the entrance to the Main Building, is a comfortable place to wait for a ride or to relax between appointments. There is free coffee, a water bottle refilling station and a charging station. It includes a small business center, with available work areas, a computer and a printer. A small conference room is available to be reserved. Hospitality navigators, bilingual in Spanish and Arabic, are available to help families find lodging, restaurants, activities and other local services. You can reach navigators at 215-590-2499.
HELP WITH FINANCIAL MATTERS
HELP WITH FINANCIAL MATTERS

We encourage you to talk to the oncology financial liaison about questions and concerns related to insurance. Your social worker can also talk to you about available resources. Visit chop.edu/financial-matters to find information that will help you:

- Understand your health insurance
- Manage healthcare finances
- Answer frequently asked questions
- Find resources for your family
- Understand health insurance terms (glossary of terms)

The Family Health Coverage Program is a program to help uninsured and underinsured families get the financial assistance they need. Your family will be assigned a coordinator who can help you apply for available public and private insurance programs and, if applicable, CHOP’s Financial Assistance program (chop.edu/services/financial-assistance). You can call the Family Health Coverage Program at 1-800-974-2125.

CHIP

The Children’s Health Insurance Program (CHIP) is designed for families that earn too much money to qualify for Medicaid, yet cannot afford to buy private insurance for their children. CHIP coverage provides eligible children with coverage for a full range of health services including regular checkups, immunizations, prescription drugs, lab tests, X-rays, hospital visits and more.

Family Medical Leave Act (FMLA)

www.dol.gov/whd/regs/compliance/1421.htm

- Entitles employees to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage.
- Offers 12 work-weeks of leave in a 12-month period that can be taken continuously or intermittently
- Employee must have worked for your employer for a minimum of 12 months (does not have to be in a row) and for 1,250 hours (24 hours a week for one year).
- Your employer must have 50 employees within 75 miles of where you work.
- New Jersey offers a partial paid time off for the first 6 of the 12-week job-protected leave.

Supplementary Security Income (SSI)

www.ssa.gov

- SSI is a federally funded program that provides monthly payments to the elderly, and blind and disabled children and adults if medical and financial eligibility criteria are met.
- If a child is eligible, he also automatically qualifies for Medical Assistance/Medicaid (MA) to help pay for medical expenses.
- You can apply at your local Social Security Administration office, or by phone at 1-800-772-1213.

Pennsylvania Medical Assistance (PA-MA)

www.dhs.pa.gov/citizens/healthcaremedicalassistance

- This is a state program that helps families that qualify pay for medical expenses. Due to a provision in the laws regarding Medical Assistance, children with serious disabilities who live in Pennsylvania are eligible for Medical Assistance (also known as Medicaid) regardless of their parents’ income.
- Apply at your local county assistance office or online; www.dhs.pa.gov/applyforbenefits
- Or apply through CHOP Family Health Coverage: 800-974-2125
- Apply for Medical Assistance for “children with severe disability” under PH 95.
- Your social worker can provide further guidance.

continued >
HELP WITH FINANCIAL MATTERS

New Jersey Catastrophic Illness in Children Relief Fund
www.state.nj.us/humanservices/cicrf
- Provides eligible families with financial assistance to help them cover medical expenses that were previously incurred because their child became catastrophically ill or injured.
- Call 1-800-335-3863 or apply online from the home page.
- Patients must be under 21, live in New Jersey for three months and have medical expenses more than 10 percent to 15 percent of income.

New Jersey Disability Insurance
lwd.dol.state.nj.us/labor/tdi/tdiindex.html#TDI2
- Call 609-292-7060 or apply online:
- Must file within 30 days from the first day of the start of your “disability.”
CANCER RESOURCES
CANCER RESOURCES

Below is a list of community resources that other families have found to be helpful. There are many other programs, agencies and organizations that we have not listed that may be useful for your family. For more information, contact your social worker.

ACOR – The Association of Cancer Online Resources Inc.
www.acor.org ; www.acor.org/ped-onc
ACOR offers information and e-support groups to patients, caregivers or anyone else looking for answers and support related to cancer. ACOR hosts several pediatric discussion groups. The website provides disease and treatments descriptions, and links to pertinent information.

Alex's Lemonade Stand Foundation Travel for Care Program
www.alexslemonade.org/travel-for-care
Recognizing the financial burden that families often encounter, the Alex’s Lemonade Stand Travel for Care Program offers assistance to families that face the need to travel for childhood cancer treatment. Transportation, lodging and meal accommodations are available to eligible families that meet the criteria. Applications must be received on behalf of a social worker or another medical representative.

American Cancer Society (ACS)
www.cancer.org
The ACS sponsors support groups for patients, parents and siblings and may also be able to help with nonmedical expenses such as wigs, transportation, wheelchairs, hospital beds and nonmedical bills. ACS is based in each county; services may vary from chapter to chapter. Call 1-888-227-5445 or visit online. They also offer a program for adolescents and young adults (AYAs) called Look Good, Feel Better, which teaches cancer patients hands-on cosmetic techniques to help them cope with appearance-related side effects from chemotherapy and radiation treatments. Ask your social worker about program dates and times here at CHOP!

The American Society of Clinical Oncology
www.cancer.net
Oncologist-approved information on more than 120 types of cancer and cancer-related syndromes is listed.

Cancer Care
www.cancercare.org
This resource provides professional counseling and guidance to families and financial assistance to eligible families to help with certain home care, transportation and medical treatment costs and childcare. For information call 1-800-813-HOPE or visit online.

Cancer Support Community of Greater Philadelphia
www.cancersupportphiladelphia.org
The Cancer Support Community of Greater Philadelphia is a nonprofit organization serving people with cancer and their loved ones of all ages and ethnicities throughout the five-county area. Services include support to people with all types of cancer and their families, educational workshops, healthy lifestyle programs and social activities.

CarePages – CHOP
www.carepages.com/chop
The simple-to-use, online service helps family and friends stay in touch during a child’s hospitalization and recovery. With a CarePage, you can share news and updates about your child, receive messages of support from friends and family on your own message board, post visiting hours and contact information, and share photos with friends and family.

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CANCER RESOURCES  continued

CaringBridge
www.caringbridge.com
This site that allows parents to create a free web page about their child. Parents can keep a virtual diary of how they are doing. It can be updated at any time, and friends and family can access it from any web browser. It’s very user friendly.

Chai Lifeline
www.chailifeline.org
Through programs that address the emotional, social and financial needs of seriously ill children and their families, Chai Lifeline restores normalcy to family life and better enables families to withstand the crises and challenges of serious pediatric illness.

Chemo Angels
www.chemoangels.com
If your child’s application is accepted, they will be “adopted” by a Chemo Angel who, through cards, cheerful notes, small gifts, etc., will provide support and encouragement throughout treatment.

Childlink
www.phmc.org
This agency coordinates services in Philadelphia and helps children from birth to age 3 who have special needs or who may have developmental delays. Childlink can help families receive a wide range of early intervention services in Philadelphia. For more information call 215-731-2110 or visit its website and click on “programs” and scroll down to “Children with special needs.”

Children’s Oncology Group (COG)
childrensoncologygroup.org
The Children’s Oncology Group (COG), a National Cancer Institute-supported clinical trials group, is the world’s largest organization devoted exclusively to childhood and adolescent cancer research. The COG provides important information for children and their families from the time of diagnosis, through treatment and following cure.

Education Law Center
www.elc-pa.org
Provides free legal assistance to parents, students and advocates on education law matters, and advises parents of their rights to special services under the law. The center publishes a free guide for parents, “The Right to Special Education in Pennsylvania.” For more information call 215-238-6970 or visit online.

Fertile Hope
fertilehope.org
A national, nonprofit organization dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Gilda’s Clubs
The group provides a meeting place for families to learn how to live with cancer. Services include groups, activities and workshops for all age groups. All services are free.
• Bucks/Montgomery County – 200 Kirk Road, Warminster, PA 18974, 215-441-3290, cancersupportphiladelphia.org
• South Jersey – 300 Shore Road, Linwood, NJ 08221, 609-926-2699, www.gildasclubsouthjersey.org

Imerman Angels
www.imermanangels.org
A federally registered 501(c)(3) nonprofit organization providing one-on-one cancer support: connecting cancer fighters, survivors and caregivers. Imerman Angels partners a person fighting cancer with someone who has beaten the same type of cancer. One-on-one relationships give a fighter the chance to ask personal questions and get support from someone who is uniquely familiar with their experience.

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CANCER RESOURCES continued

Kolbe Fund: Hopeful Nights Program  
www.thekolbefund.org/programs  
The Kolbe Fund provides lodging and parking accommodations for families traveling to receive medical care for their sick child. Referrals are made through the Ronald McDonald House and Hospital social workers.

The Leukemia & Lymphoma Society (LLS)  
www.lls.org  
The LLS has a Patient Aid Program ($500 per year) that can help with things such as transportation costs to and from medical appointments or medications not covered by insurance. It also offers a co-pay assistance program for certain diagnoses. Call and ask for the patient services manager:  
• Northern New Jersey: 908-956-6600  
• Southern New Jersey: 856-638-1250  
• Pennsylvania: 610-238-0360

Lotsa Helping Hands  
www.lotsahelpinghands.org  
Create a free, private, web-based community to organize family, friends, neighbors, and colleagues — a family’s “circles of community” — during times of need. Easily coordinate activities and manage volunteers with its intuitive group calendar. Communicate and share information using announcements, messages boards and photos.

Make-A-Wish Foundation  
www.wish.org  
The Make-A-Wish Foundation is a nonprofit organization that arranges experiences described as “wishes” to children with life-threatening medical conditions. Contact your social worker for more information.

Momcology  
www.momcology.org/  
Momcology is national nonprofit organization that facilitates peer support for parents and primary caregivers of children who have been diagnosed with pediatric cancer. There is a subgroup of Momcology for CHOP families.

National Cancer Institute  
www.nci.nih.gov  
This site offers research-based information about cancer for patients, the public and the media. Features research updates, plus advice on prevention and early detection.

The National Children’s Cancer Society (NCCS)  
thenccs.org  
NCCS can help to provide financial assistance to families for nonmedical expenses such as travel reimbursement, meals for inpatient hospital stays, phone cards and lodging. Call 1-800-5-FAMILY or visit online.

Oncolink  
www.oncolink.org  
Oncolink offers a variety of cancer-related information, including articles and writings by patients and their families. Also there is a children’s art gallery.

Pediatric Brain Tumor Foundation (PBTF)  
www.curethekids.org  
The PBTF is the world’s largest nonprofit solely dedicated to the pediatric brain tumor community, serving more than 28,000 children and teens in the United States who are living with a brain tumor diagnosis. PBTF offers free educational resources about brain tumors, a toolkit for newly diagnosed families, college scholarships and much more.
CANCER RESOURCES  continued

The Special Kids Network
www.gotoskn.state.pa.us
This agency provides information to families in Pennsylvania regarding special health issues and community resources. It also links families facing similar experiences together. For more information call 1-800-986-4550 or visit online.

Summer Camps
There are several camps for cancer patients, siblings and entire families. Contact your social worker for more information.

RESOURCES FOR CHILDREN AND TEENS

AYA FAQs: Answers to Your Questions
There are printed copies of this pocket guide available from your CHOP team. An online version is available at: media.chop.edu/data/files/pdfs/aya-qa-brochure.pdf

AYA Cancer Chat: Life Interrupted
Podcast available in iTunes, and at: chop.edu/health-resources/aya-cancer-chat-life-interrupted
Listen in as adolescents and young adults (AYA) from the Cancer Center at Children’s Hospital of Philadelphia discuss their experiences with cancer diagnosis and treatment.

CancerKids
www.cancerkids.org
This site tells the personal stories of children fighting many different types of cancer.

Group Loop
www.grouploop.org
Group Loop provides online support, information and resources for teens living with cancer and their families.

Next Step
www.nextstepnet.org
This organization is for teens and young adults with cancer and life-threatening blood diseases and offers retreats and workshops around the country.

Starlight Children’s Foundation
www.starlight.org
The Starlight Children’s Foundation is dedicated to improving the quality of life for children with chronic and life-threatening illnesses and life-altering injuries by providing entertainment, education and family activities that help them cope with the pain, fear and isolation of prolonged illness.

Songs of Love
www.songsoflove.org
Free, personalized songs are created for chronically ill children and young adults. Ask your social worker for an application or download one from the website.

Starbright World (part of the Starlight Foundation)
www.starbrightworld.org
This site offers an online social network for teens with chronic and life-threatening illnesses and their siblings.

Teens Living with Cancer
www.teenslivingwithcancer.org
This site is for teens with cancer, providing information on coping with hair loss, friends, family, school and much more.

2bme
www.2bme.org
Teens with cancer can find information on nonmedical topics from skin and hair issues to fitness and friends.

ONCOLOGY FAMILY HANDBOOK  33
CANCER RESOURCES  
continued

RESOURCES FOR YOUNG ADULTS (18+)

CancerCare for Young Adults
www.cancercare.org/get_help/special_progs/young_adults.php
This site offers specialized services for young adults, caregivers and those who have lost a loved one.

Fertile Hope
www.fertilehope.org
This national, nonprofit organization is dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

First Descents
www.firstdescents.org
This organization provides whitewater kayaking and other outdoor adventure experiences to promote emotional, psychological and physical healing for young adults with cancer.

Stupid Cancer
stupidcancer.org
The goal of this organization is to support a global network of patients, survivors, caregivers, providers and advocate to ensure that no one affected by young adult cancer is unaware of the age-appropriate resources they are entitled to so they can get busy living.

LiveStrong Young Adult Alliance
www.livestrong.org
This coalition of organizations has the goal of improving survival rates and quality of life for young adults between the ages of 15 and 40 with cancer.

Prepare to Live
www.preparetolive.org
This site strives to be a reliable source of “Help, Hope, Information and Inspiration™” for young adult patients, survivors and caregivers coping with cancer worldwide.

Rise Above It
www.raibenefit.org
Providing meaningful support to adolescents and young adults affected by cancer is this group’s aim. It also provides financial assistance to 15- to 39-year-olds either undergoing or actively pursuing Phase I, II or III clinical trial treatment options.

The Ulman Cancer Fund for Young Adults
www.ulmanfund.org
The fund provides support programs, education and resources for young adults with cancer and their families and friends.

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CANCER RESOURCES continued

JUST FOR SIBLINGS

Sibology
sibology@email.chop.edu
This program, facilitated by CHOP Oncology child life specialists, brings together brothers and sisters, ages 7 through 12, of cancer patients to meet and talk about what it’s like to have a sibling with a cancer diagnosis. Email for information.

Sibshops
www.siblingsupport.org
Part of the Sibling Support Project, Sibshops are interactive workshops for siblings of kids with special needs. It focuses on peer support and celebrates the many contributions made by brothers and sisters of kids with special needs. Ask your social worker for more information.

SuperSibs
www.supersibs.org
Siblings of children diagnosed with cancer find support and recognition from this Alex Lemonade Stand Foundation-sponsored site. For more information, please ask your social worker.

HAIR LOSS RESOURCES

Friends Are By Your Side
friendsarebyyourside.com
A consortium of beauty industry leaders, salon owners and stylists donate hair replacement and styling services to girls and women undergoing cancer treatment.

Hair Club for Kids
www.hairclub.com/hairclub-for-kids
The group provides free hair restoration for children battling hair loss as a result of illness.

Headcovers Unlimited
www.headcovers.com
This is a source for hats, turbans and wigs for hair loss and cancer patients.

Hip Hats with Hair
www.hatswithhair.com
An organization that provides hats with human or synthetic hair attached for girls whose hair loss is due to chemotherapy.

Locks of Love
www.locksoflove.org
Lock of Love is an organization that provides hairpieces to children under age 18 suffering from long-term medical hair loss from any diagnosis.

Wigs for Kids
www.wigsforkids.org
This organization provides wigs and accepts hair donations.

Wiggalicious
www.wigliciouswigs.com
The “Angels of Wiggalicious” program provides free or low-cost wigs to women and girls who have lost hair due to chemotherapy.