

## 2012 Annual Report

Pediatric Brain Tumor Program — *A focus on medulloblastoma*  
OHSU Cancer Committee



Pediatric neurosurgeons Dr. Nathan Selden and Dr. Lissa Baird in the operating room with their team.

# OHSU Cancer Committee 2012 Annual Report

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Our vision to provide world-class, compassionate, individualized care for all is enhanced by our growth in the number of multidisciplinary clinics offered.

Dear Colleagues,

As part of our commitment to improving cancer care, Oregon Health & Science University annually reviews the progress we are making on behalf of patients. This report allows us to track how a program improvement impacts our patients' treatment outcomes and their quality of life.

This dedication to improvement enabled the OHSU Knight Cancer Institute to earn accreditation with full commendation from the American College of Surgeons' Commission on Cancer. That accreditation, which is the highest achievable, signifies that the OHSU Knight Cancer Institute's programs meet all 36 standards set by the Commission on Cancer to improve cancer care outcomes.

But solving the problem of cancer is not something any one institution can do on its own. The OHSU Knight Cancer Institute is on the forefront of research that is cataloging just how complex this disease really is. Because of that, we know that collaboration is essential to advancing personalized cancer medicine. The disease, at the molecular level, is as individual as the person it has impacted and care programs need to be designed with those differences in mind.

This year's report, a focus on medulloblastoma, is in that spirit. We are showcasing the work of the OHSU Knight Cancer Institute's counterparts in pediatric and young adult cancer care at OHSU Doernbecher Children's Hospital. Learning how to meet the needs of these young patients can help inform how we improve cancer care for adults too.

Sharing research, lessons learned and clinical resources is deeply ingrained in the OHSU Knight Cancer Institute's mission to end cancer as we know it. We look forward to working even more closely together to transform cancer into a treatable disease that patients and their families will no longer have to fear.

Sincerely,

*Kevin Billingsley, M.D.*

*Chairman, OHSU Cancer Committee*

*Hedinger Professor of Surgery and Chief of the Division of Surgical Oncology*

*OHSU Knight Cancer Institute*



**Nurse practitioner  
Christopher Conrady  
with Sam Lockard**

Caring for kids and families is an incredible gift from Doernbecher to the community. Their support and genuine caring have made a big difference in Sam's positive outcome.

## Caring for a Child...and a Family

At just five years old, Sam Lockard is already a survivor. He's been through a craniotomy, 31 radiation treatments and multiple chemotherapy cycles. But today, getting maintenance chemo at OHSU Doernbecher Children's Hospital, Sam's biggest concern is a snack. "Mom, can I have a cookie?"

"Of course!" says mom Jen Clason. While Sam gets treatment — he's near the end of six four-week cycles of cyclophosphamide, cisplatin and vincristine — volunteers and nurses stop by with smiles and hugs.

It's been a short, turbulent ride since Sam developed vomiting and headaches last spring. After ruling out stomach flu and checking his vision, pediatrician Deborah Fuerth, M.D., sent Sam for an MRI at McKenzie-Willamette Medical Center, where Clason is a nurse. By that evening, Clason and her son were at OHSU Doernbecher Children's Hospital, where a shunt was placed to relieve the hydrocephalus a tumor was causing in Sam's brain.

Nathan Selden, M.D., Ph.D., did a craniotomy a few days later. "I was totally freaked out," Clason says. "I needed to use the clinical side of my

brain instead of the emotional side, just so I could hold it together. Dr. Selden was able to go right there with me, and get me the information I needed."

There was good and bad news: children Sam's age often have the best prognosis with this high-grade tumor, and Sam had no metastases. But he had anaplastic (large-cell) medulloblastoma, an aggressive type that prompted more intensive therapy.

Treatment has been challenging. "Sam gets profoundly pancytopenic and requires a lot of transfusions," Clason says. He also had sepsis and a subdural hematoma. As a nurse, Clason was hypervigilant at first. "It's well known that nurses and their families are hard to care for," she says. "We're exacting. But the Doernbecher staff does a great job."

Sam's team includes Carol Marquez, M.D., of OHSU Knight Cancer Institute's Radiation Medicine and Kellie Nazemi, M.D., director of pediatric neuro-oncology at Doernbecher.

"The doctors are fabulous," Clason says. "Dr. Nazemi's incredibly smart, but also very real. She truly listens, and she plays

with Sam." Selden is "a neurosurgeon you can have a human conversation with — that's special," Clason laughs. "The doctors ask me, 'How are you coping? What can we do better?'"

The Doernbecher staff is "outstanding. From the nurses and techs to the people who bring Sam room service, we feel they genuinely care about us." Volunteers can stay with Sam during treatments, freeing Clason to talk to doctors or take a break. "If I'm not stressed, Sam doesn't have to respond to my stress, and that helps him," she says. "They take care of the whole family here."

As for Sam, he is busy telling the story of how Doernbecher nurse practitioner Christopher Conrady put one of Sam's Angry Birds temporary tattoos on his own forehead. Clason laughs, and says Sam will probably be ready for kindergarten next fall. Despite the setting, it feels like a stress-free moment. For a five-year-old survivor, that can only be good.

*To read other inspiring stories from OHSU Knight Cancer Institute cancer patients, please visit:*  
[www.ohsuknightcancer.com](http://www.ohsuknightcancer.com).



Nathan Selden, M.D., Ph.D.; Lissa Baird, M.D.; Kellie Nazemi, M.D.; H. Stacy Nicholson, M.D.; and team members at a Tumor Board meeting.

## A Team Approach to Treating Medulloblastoma

OHSU Doernbecher Children's Hospital offers the most comprehensive treatment for children and adolescents with central nervous system tumors in Oregon and southwest Washington. Multiple subspecialists with brain tumor expertise come together in teams that are customized for each patient. Doernbecher provides multidisciplinary care that is centered on the child.

### A MEDULLOBLASTOMA PRIMER

Medulloblastoma is the most common malignant brain tumor in children. Approximately 20 percent of pediatric CNS tumors are medulloblastoma. In children younger than 15, the incidence is estimated at 0.5 per 100,000. Peak occurrence is between ages four and seven, but at least 30 percent of medulloblastomas occur in patients older than 15.

A common clinical presentation is:

- A two- to-four-week history of headaches with or without vomiting — These symptoms are frequently attributed to a common childhood illness, such as influenza or another viral illness.
- Worsening symptoms over two to three weeks, rather than the improvement typically seen with a common illness.

- Localized neurologic abnormality such as ataxia or cranial nerve dysfunction (usually an eye movement abnormality).

Symptoms may prompt referral for MRI, often in the emergency department.

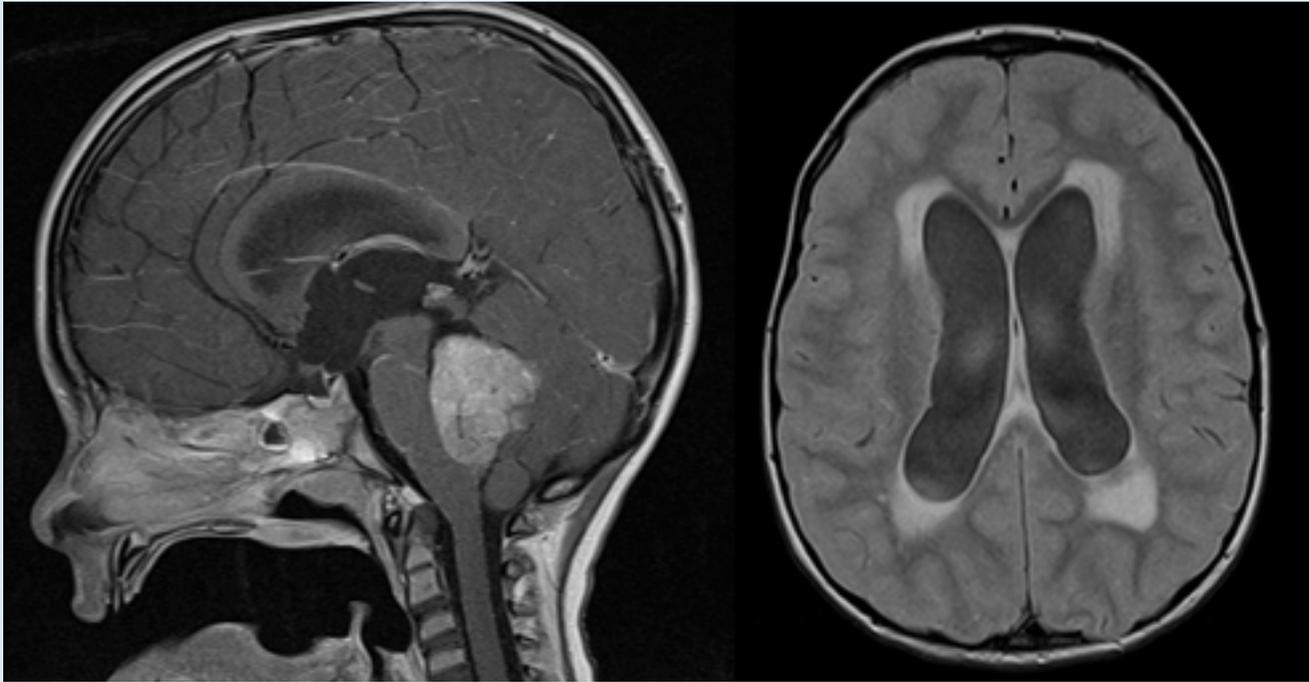
### MEDULLOBLASTOMA TREATMENT AT OHSU DOERNBECHER

The long-term cure of medulloblastoma requires surgery, radiation and chemotherapy. A unified team is essential to coordinate therapy successfully.

Typically, patients are first admitted to Doernbecher's pediatric neurosurgery service. Admission is often coordinated with the pediatric intensive care unit to allow close monitoring in the perioperative period. The most immediate treatment goal is relieving increased intracranial pressure caused by tumor obstruction of cerebrospinal fluid outflow. This often requires placement of an external ventricular drain to divert CSF.

The next step is maximal safe surgical resection of the tumor. Complete resection is often achieved, but a small amount of residual disease may be tolerated in some situations because medulloblastoma responds well to radiation and chemotherapy. Surgical goals include preserving neurologic function.

**Figure 1. At left, MRI (sagittal view, T1 post-gadolinium) showing a medulloblastoma in the classic location: arising from the cerebellum and growing into the 4th ventricle. At right, MRI (axial view, FLAIR sequence) showing hydrocephalus caused by obstructed flow of cerebrospinal fluid at the 4th ventricle.**



The pediatric neuro-oncology team meets the child and family around the time of surgery, beginning to establish a relationship even before the diagnosis is known. The team includes a pediatric neuro-oncologist, neuro-oncology pediatric nurse practitioner and medical social worker. This team works closely with the family during the challenging transition from having a sick child who is recovering from major surgery to knowing the name of the tumor and beginning the appropriate treatments.

Once the tumor is resected, neuropathology receives the tumor specimen to establish a diagnosis. Each patient's case is reviewed in detail at a weekly Pediatric Neuro-Oncology Tumor Board attended by team members from neurosurgery, neuro-oncology, radiation oncology, neuroradiology and neuropathology. The presenting symptoms and operative findings are discussed. Then neuroradiology shows the perioperative imaging and neuropathology shows the pathology slides. A unified treatment plan is decided with all the experts in one room.

Once the team has decided on a treatment plan, the neuro-oncologist sits down with the family for a prolonged period of education about the diagnosis, prognosis, need for further evaluation and a detailed treatment plan. This typically happens during the initial hospitalization, but may also be done on an outpatient basis. When appropriate, a face-to-

face interpreter is available to help. The family also meets with the pediatric radiation oncologist to initiate treatment planning. After tumor resection, procedures include:

- Spinal MRI and lumbar puncture to look for metastases.
- Placement of a central line ("Port-a-Cath") to allow safe delivery of chemotherapy and make frequent blood draws easier for the child.
- Most children start radiation and chemotherapy three to four weeks after tumor resection (see timeline).

#### **PEDIATRIC NEURO-ONCOLOGY: COORDINATING MEDULLOBLASTOMA CARE**

Medulloblastoma care at OHSU Doernbecher is centrally coordinated through pediatric neuro-oncology. The team members in the Division of Pediatric Hematology-Oncology dedicated to brain tumor care are:

##### **Neuro-oncologists:**

**Kellie Nazemi, M.D.**, Director, Pediatric Neuro-Oncology

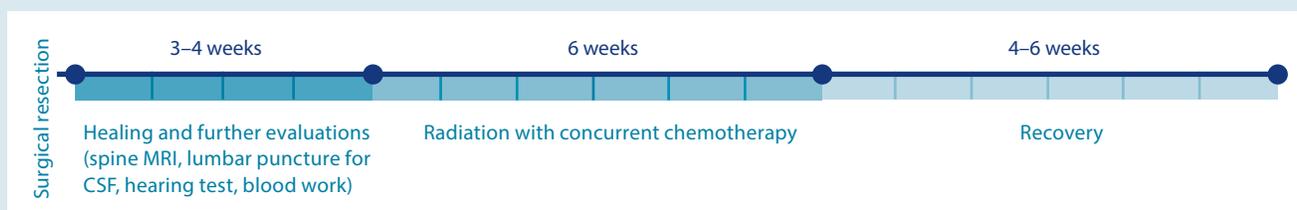
**H. Stacy Nicholson, M.D., M.P.H.**, Physician-in-Chief of Doernbecher and Chairman of Pediatrics (sees brain tumor patients in long-term follow-up)

##### **Pediatric oncologists with brain tumor expertise:**

**Thomas Lamkin, M.D.**

**David Tilford, M.D.**

## Standard Approach for Initial Therapy of Medulloblastoma



Above is a sample timeline for initial therapy of medulloblastoma. The radiation field includes the entire craniospinal axis because of the risk of metastatic recurrence in the rest of the brain or spine. A higher dose of radiation is delivered at the site of the original tumor. The radiation dose depends on the risk category. Either one or two chemotherapy drugs or agents will be used during this time.



Above is a sample timeline for maintenance chemotherapy after initial medulloblastoma treatment. The duration of maintenance chemotherapy depends on risk category. Patients are routinely admitted to the hospital for delivery of chemotherapy

**Nurse practitioner:** Christopher Conrady, R.N., P.N.P.

**Primary nurses:** Ann Houck, R.N., Lily Doebler, R.N.

**School liaison and teacher:** Anna Balmaseda

**Medical social worker:** Shirley Mason, M.S.W.

**Clinical research associate:** Kitt Swartz, M.P.H.

**Specialized scheduling staff:** Carla Spehar

**Program coordinator:** Kenna Conklin

The pediatric neuro-oncology team holds a weekly team meeting at which the upcoming week's clinic schedule is reviewed and a detailed plan for each patient's visit is made. The team also coordinates patients' needs for follow-up in other departments, finalizes plans for chemotherapy and lab draws and addresses any complex scheduling needs.

### WHAT HAPPENS AT A NEURO-ONCOLOGY CLINIC VISIT?

Each patient has surveillance imaging (usually MRI of the brain, spine or both) done before a clinic visit. The neuro-oncology team personally reviews images with neuro-radiology before clinic. This allows the team to give families results almost immediately after the scan, minimizing the anxiety involved with waiting for results.

The pediatric neuro-oncology clinic has specialists available for consultation or follow-up, and each patient's visit is specifically tailored to the practitioners he or she needs to

see. For example, a patient might see an endocrinologist, neurologist or neurosurgeon as well as other members of the neuro-oncology team.

Other resources and support are also available, including the medical social worker, the school liaison, a pharmacist and a dietician. The patient and family might talk to a social worker on a range of topics from how siblings are handling a child's illness to finding gas money for the trip to Doernbecher. The school liaison, a licensed teacher, is available to help students keep up with classes, reintegrate into school or both. Children undergoing outpatient radiation therapy or inpatient chemotherapy often attend the in-hospital school located near the oncology unit and clinic.

### ACHIEVING CURES THROUGH INDIVIDUALIZED THERAPY

The goal of medulloblastoma treatment is cure. The details of treatment depend on each patient's risk of recurrence. Traditionally, this risk was calculated simply by the patient's age, the presence of metastases and the degree of surgical resection. Today, risk stratification is increasingly complex as researchers identify new histologic and even molecular subtypes of medulloblastoma. Input from all members of a focused, transdisciplinary team with expertise and depth of knowledge is invaluable in curing these patients with the fewest possible long-term side effects.

**LOOKING TO THE FUTURE: LONG-TERM FOLLOW-UP**

While medulloblastoma therapy can be curative, late effects of treatment are not uncommon. The pediatric neuro-oncology team begins working to mitigate such effects shortly after therapy is complete. For example, endocrine system effects often include growth hormone deficiency and thyroid dysfunction. All patients are seen by Lisa Madison, M.D., a pediatric endocrinologist with brain tumor expertise, for baseline evaluation. After that, patients see Dr. Madison every six months in the pediatric neuro-oncology clinic.

Patients also have a neuropsychology assessment with a pediatric psychologist for evaluation of cognitive difficulties related to radiation therapy. Common problems include decreased processing speed and problems with working memory, attention and concentration. The school liaison and teacher, Anna Balmaseda, sends detailed reports to schools to convey individualized education plans and help parents advocate for their child’s needs.

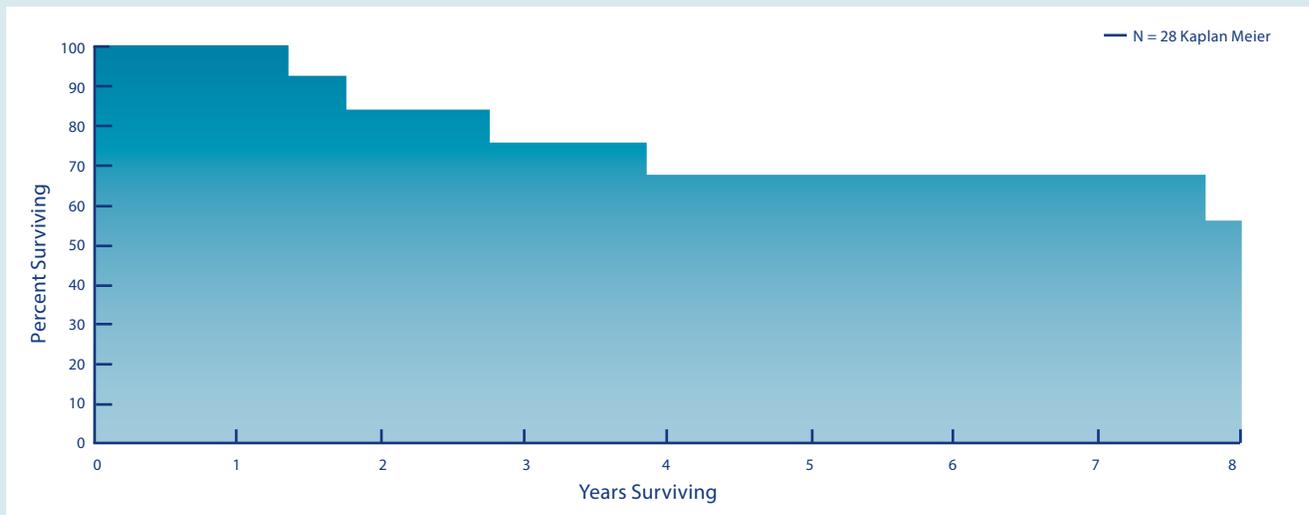
After patients complete therapy, the pediatric neuro-oncology team initiates a routine surveillance-imaging schedule in order to assess disease status at regular intervals. Most medulloblastoma recurrences happen within two years, but late recurrences are possible. The typical surveillance schedule is:

- First year off therapy: MRI every three months
- Second year off therapy: MRI every four months
- Third year off therapy: MRI every six months

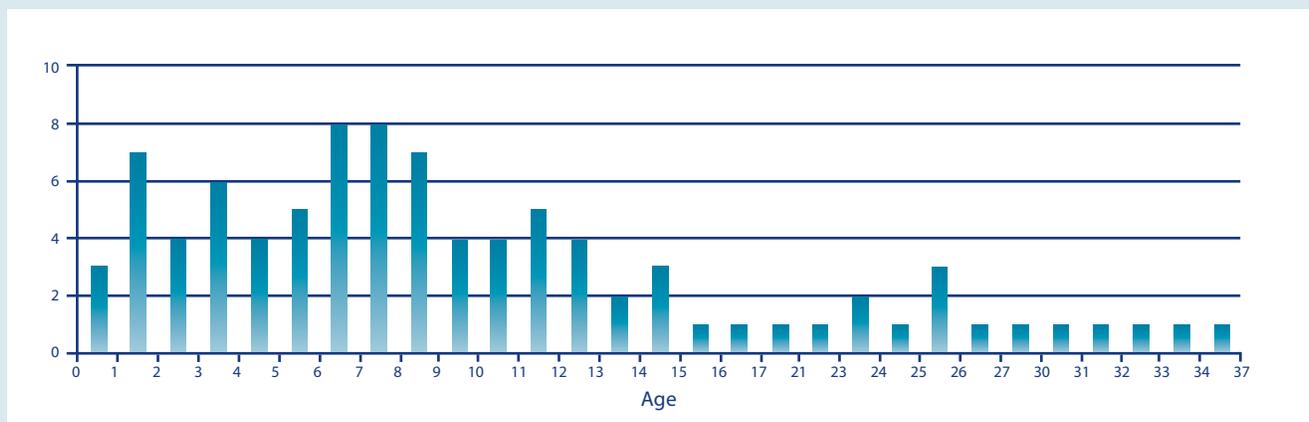
After three years, patients have a yearly MRI for at least five years. All patients continue to have an annual clinic visit.

Between three and five years after completing therapy, patients are referred to Doernbecher’s Survivorship program. This program focuses on life after brain tumor treatment (see related story page 13).

**Graph 1 — 8 year overall survival rates for medulloblastoma at OHSU Doernbecher**



**Graph 2 — OHSU Medulloblastoma Cases, Age at Diagnosis**





## Pediatric Brain Tumor Team

Doernbecher's neuro-oncology program is unique in Oregon. We provide comprehensive care with a multidisciplinary, highly individualized approach in partnership with OHSU's Knight Cancer and Brain Institutes. Led by nationally recognized pediatric neuro-oncology expert Kellie Nazemi, M.D., the OHSU Doernbecher team includes experts from the following disciplines.

### Neuro-Oncology

**Kellie J. Nazemi, M.D.**, Pediatric Neuro-oncologist and Director, Pediatric Neuro-Oncology

**H. Stacy Nicholson, M.D., M.P.H.**, Pediatric Neuro-oncologist, Physician-in-Chief and Chair, Doernbecher Children's Hospital

**Thomas Lamkin, M.D.**, Pediatric Hematologist/Oncologist, Kaiser Permanente

**David Tilford, M.D.**, Pediatric Hematologist/Oncologist, Outpatient Clinic

**Christopher Conrady, R.N., P.N.P.**, Pediatric Neuro-oncology Nurse Practitioner

### Neurosurgery

**Nathan Selden, M.D., Ph.D., F.A.C.S., F.A.A.P.**, Pediatric Neurosurgeon, Vice Chair, OHSU Department of Neurosurgery

**Lissa Baird, M.D.**, Pediatric Neurosurgeon

**Wendy Domreis, R.N., M.S., C.P.N.P.**, Pediatric Neurosurgery Nurse Practitioner

**Laurie Yablon, R.N., M.S., C.P.N.P.**, Pediatric Neurosurgery Nurse Practitioner

**Joylyn Michaud, R.N., F.N.P.**, Pediatric Neurosurgery Nurse Practitioner

### Radiation Oncology

**Carol Marquez, M.D.**, Pediatric Radiation Oncologist, OHSU Knight Cancer Institute

### Neuroradiology

**Jim Anderson, M.D.**, Neuro-radiologist (Pediatric focus)

**Dianna Bardo, M.D.**, Neuro-radiologist (Pediatric focus)

### Neuropathology

**Marjorie Grafe, M.D.**, Medical Director, Neuropathology

**Sakir Gultekin, M.D.**, Neuropathologist

**Randy Woltjer, M.D.**, Neuropathologist

### Pediatric Endocrinology

**Lisa Madison, M.D.**, Pediatric Endocrinologist (Brain tumor expertise)

### Pediatric Neurology

**Jason Coryell, M.D.**, Pediatric Neurologist (Brain tumor expertise)

### Pediatric Neuro-ophthalmology

**Julie Falardeau, M.D.**, Neuro-ophthalmologist

**William Hills, M.D.**, Neuro-ophthalmologist

### Pediatric Ophthalmology

**Daniel Karr, M.D.**, Pediatric Ophthalmologist

**Leah Reznick, M.D.**, Pediatric Ophthalmologist

**Ann Stout, M.D.**, Pediatric Ophthalmologist

### Neuropsychology

**Mina Nguyen-Driver, Psy.D.**, Pediatric Psychologist

### Pediatric Audiology

**Kristin Knight, C.C.C.-A.**, Pediatric Audiologist

**Heather Durham, M.S., C.C.C.-A.**, Pediatric Audiologist

**Lyndsay Duffus, Au.D., C.C.C.-A.**, Pediatric Audiologist

**Natasha Carmichael, C.C.C.-A.**, Pediatric Audiologist

**Iris Spears, C.C.C.-A.**, Pediatric Audiologist  
**Survivorship**

**Susan J. Lindemulder, M.D.**, Director, Survivor Program, Pediatric Hematology-Oncology

**Kelly Anderson, R.N., F.N.P.**, Nurse Practitioner, Survivor Program

### Bridges Palliative and Comfort Care Program

**Gregory Thomas, M.D.**, Medical Director

**Kathy Perko, R.N., M.S., P.N.P.**, Program Director

**Bryan Gish, M.S.W.**, Social Worker

### Pediatric Neuro-Oncology Staff

**Ann Houck, R.N.**

**Lily Doebler, R.N.**

**Shirley Mason, M.S.W.**

**Anna Balmaseda**, School Liaison and Teacher

**Carla Spehar**, Scheduling

**Kenna Conklin**, Program Coordinator

**Kitt Swartz, M.P.H.**, Clinical Research Associate

To find out more about the program, or to refer a patient, please call **503 346-0640** or toll-free at **877 346-0640**.



Pediatrician Pilar Bradshaw, M.D., with a young patient and his mother.

## My Perspective — by Pilar Bradshaw, M.D., Pediatrician

One of the hardest conversations for me to have with a family is the one in which I share the news that their child has a brain tumor. As a pediatrician and a mother, I struggle to keep my own emotions together when I see the fear in the parents' eyes. But after telling them the diagnosis, I always follow with, "I have already talked to the specialists at OHSU. I would trust Dr. Nazemi and Dr. Selden with the lives of my own children. They are amazing, and their team will take the best care of your little one."

So has gone the conversation four times in a span of less than two years in my practice. Four new diagnoses of brain tumor in four children I care for at Eugene Pediatrics, located more than 100 miles from the children's cancer team at Doernbecher. But distance does not matter nearly as much as it used to, thanks to technology and the approach of Dr. Nazemi and Dr. Selden's team.

Communication is the key. MRI images sent digitally to OHSU. Faxes sent between my office and Doernbecher and back. OHSU Connect messages sent immediately when patients are seen. Instant access by phone, 24-7. All of these modes of sharing information quickly make it possible for me to extend the care of the cancer treatment team when kids with brain tumors present to my office for help. But beyond the technology itself, is how these doctors use it. Late nights or weekends, whenever I have called, they respond. Dr. Nazemi and I have spoken as she was boarding an airplane, or attending a meeting on the other side of the country.

Dr. Selden has spent 45 minutes talking to me from his home on a holiday when most people with a more normal job would have cut the conversation short and gratefully chucked their pager in the back of a drawer.

The collaboration goes both ways. When one of these families was facing a dire end-of-life decision point, I was able to help the treatment team by reaching out and talking several times to the parents by phone. My long years of knowing them prior to the diagnosis of cancer made it easier for me to talk about the hardest moment in their life. The advice of their specialists, reinforced by the perspective of their pediatrician, made it possible to bring their son home on hospice to a peaceful passing.

The diagnosis of a brain tumor in your patient is the beginning of a journey for that family. And the beginning of a new journey for you as a pediatrician, too. I feel better knowing that I am always taking that trip in the company of a team of caregivers at Doernbecher who will bring their expertise and compassion to every interaction with that family and with me. Dr. Nazemi and Dr. Selden inspire me, and remind me that it's the human connections we make with our patients and our colleagues that make the practice of medicine so rewarding.

*Pilar Bradshaw, M.D., F.A.A.P. is a general pediatrician and owner of Eugene Pediatric Associates in Eugene, Oregon.*



Doernbecher team helps a Wallowa teen face cancer with courage and perseverance.

## A Teen's Journey to Recovery

It started with a fall on the ice. In December 2010, 15-year-old Brandy Starmer slipped and hit the back of her head. Besides having whiplash and a concussion, her mother Tonya Starmer noticed that, "Brandy wasn't her happy-go-lucky self after the fall. Her pupils were dilated, she had double vision and she would stagger and vomit often."

The Starmers, who live in Wallowa, saw Samuel Kimball, O.D., in April 2011 for Brandy's ocular symptoms. Dr. Kimball noted optic nerve swelling and sent them to neuro-ophthalmologist Julie Falardeau, M.D., at OHSU Casey Eye Institute.

After that, events moved quickly. "Dr. Falardeau sent Brandy right to Doernbecher," Tonya says. There, an MRI revealed a tumor in Brandy's cerebellum. The next day, Nathan Selden, M.D., Ph.D., removed a tumor the size of an orange. Pathology revealed the mass was a medulloblastoma.

"It was really scary, having a tumor in my head," Brandy says. Her skull was closed with metal plates: two permanent, one temporary. The temporary plate was removed in September 2012, and Brandy wears

it on a bracelet. "It's shaped like a snowflake and really pretty," she says.

After Brandy recovered from the craniotomy, she got a Port-a-Cath. Then Brandy had six weeks of radiation plus weekly chemotherapy with vincristine. During chemotherapy, she hung out with her mom and her "chemo pal" — a Doernbecher volunteer who sat with her as long as she wanted. Naps and Doernbecher bingo games helped pass the time.

During treatment, Brandy suffered from extreme nausea, and her weight dropped from 105 pounds to 82. A feeding tube helped bring her weight up, and today Brandy says her appetite is "way better." Despite the side effects and long drives, the Starmers feel going to Doernbecher was well worth it.

"Everyone at Doernbecher is loving and supportive," Tonya Starmer says. "We tried getting Brandy's labs done nearer to home, but the staff at Doernbecher were the best about managing her port and taking care of her." Brandy describes her team as "so kind." Even when the 300-mile drive took eight hours because of Brandy's frequent rest stops, mom Tonya says, "I wouldn't want to go anywhere else."

Today Brandy is cancer-free. "I'm back to school and getting my strength back," she says. A junior at Wallowa High School, she walks a half-mile each way to school and back.

Starting in 2013, the Starmers will only travel to Doernbecher every three months for MRIs. Brandy will keep seeing her team for many years to come, to monitor her health and any late effects of treatment. The survivorship program at Doernbecher will also be a resource for Brandy and her family. Based on prior experience with Brandy's type of medulloblastoma, her chances of staying in remission are very good.

Brandy reflects, "Doernbecher kind of feels like home now because I've been going there for a year. I don't even think about how long the ride takes — you just go, get there and you're done." Tonya, who has driven those miles countless times, simply says, "We're thankful this journey has been with such a good team."

## Oregon's Only Comprehensive Program for Children with Brain Tumors

Each year, we treat between 40–50 patients with newly diagnosed brain tumors and follow many more as long-term survivors.

Besides the core providers who design the treatment plan, patients receive comprehensive care through the following departments and services:

- **Pediatric neurology** — For day-to-day management of symptoms and side effects such as headaches, neurologic dysfunction or seizures. In the pediatric neuro-oncology clinic, patients regularly see Jason Coryell, M.D., a neurologist with a practice focus on brain and spinal cord tumors.
- **Neuro-ophthalmology and pediatric ophthalmology** — For eye movement disorders and effects on vision.
- **Pediatric audiology** — For tumor or treatment effects on hearing.
- **Pediatric endocrinology** — For management of therapy side effects (primarily from radiation).
- **Pediatric hematology/oncology** — For management of inpatient hospitalizations for chemotherapy or complications of therapy.
- **General surgery** — For placement of central lines.
- **Emergency department and pediatric ICU** — For emergency and intensive care when needed.
- **Physical therapy, occupational therapy and speech therapy** — Often needed in this population as a result of tumor or its treatment.
- **Pediatric psychology** — For management of emotional and psychological effects of disease or treatment.
- **Pediatric neuropsychology** — For assessment of neuro-cognitive dysfunction related to the tumor or its treatment.

## Outward Bound: Physician and Clinical Outreach

The brain tumor specialists at OHSU Doernbecher treat children from all regions of Oregon and Alaska as well as southwest Washington.

Doernbecher's collaborations with practices around the region allow children with brain tumors to receive care in the familiar settings of their home communities. For example, a collaboration with Asante Rogue Regional Medical Center in Medford, Ore., brings cancer care to southern Oregon through Ellen Plummer, M.D., a pediatric oncologist and affiliate assistant clinical professor at OHSU. A collaboration with Central Oregon Pediatric Associates in Bend, Ore., allows children to receive some components of outpatient chemotherapy there instead of traveling to Portland. In addition, a relationship with the Pediatric Oncology & Infusion Center at Alaska Providence Medical Center in Anchorage, Alaska, provides treatment delivery under the direct supervision of pediatric oncologists Laura Schulz, M.D., and Shannon Norman, M.D.

The pediatric oncology providers in Medford and Anchorage also videoconference into Doernbecher's weekly general oncology tumor board meetings. At these meetings, physicians share knowledge and make plans for the surgery, chemotherapy and radiation treatments each patient needs. This technology makes it easy for the physicians from southern Oregon and Alaska to participate.

In addition, Doernbecher physicians regularly speak to primary providers on new developments in pediatric brain tumors and other childhood cancers. Our pediatric cancer specialists have spoken about childhood cancer issues at hospitals in Coos Bay, Salem and Eugene, Ore., and Vancouver, Wash. They also visit pediatric practices to give informal presentations.

At Doernbecher Children's Hospital, an attending physician and fellow are available 24 hours a day, seven days a week for consultation with community providers. Contact us at **503 346-0644** or toll free at **888-346-0644** to consult with a Doernbecher physician or refer a patient.



Andy Koontz feels blessed to have had access to a team of OHSU specialists who provided state-of-the-art treatment and compassionate care.

## Treating Adults with “Childhood” Brain Tumors

On Twitter, Portlander Andy Koontz describes himself as a musician, filmmaker, writer and brain cancer survivor.

In 2006, Koontz, then 30, was finishing up a horror film he wrote, directed and scored when he started feeling strange. “I didn’t feel normal and didn’t know what was going on,” he recalls. He had dizzy spells, but attributed his symptoms to overwork.

Koontz’s dizziness intensified and he began suffering from nausea and vertigo. When he woke up one day and couldn’t turn his head to look at his wife, Koontz knew he was really sick. His wife Chrissy called an ambulance and he was taken to the OHSU emergency department.

At OHSU, an MRI revealed a mass on the left side of Koontz’s cerebellum. “Chrissy and I were devastated,” Koontz says. “We cried for about five minutes, but then we said, ‘We’ve got to take it on.’”

Kim Burchiel, M.D., chair of OHSU’s Department of Neurosurgery and co-founder of OHSU Brain Institute, immediately performed surgery to remove the tumor.”

After surgery, pathology results confirmed that Koontz’s tumor was medulloblastoma, a malignant tumor of childhood. While medulloblastoma occurs most frequently in elementary school-aged children, it can also occur in young adults.

At 30, Koontz was clearly in the older category of medulloblastoma patients, but he was treated at OHSU Doernbecher Children’s Hospital after surgery because Doernbecher has the leading experts in treating this cancer. Kellie Nazemi, M.D., director of pediatric neuro-oncology, took over Koontz’s case and coordinated his post-surgery health care team.

Koontz underwent 30 days of radiation to the brain and spine, followed by chemotherapy. His team was unique and customized for his specific needs, including both adult and pediatric specialists. His routine chemotherapy hospitalizations started in the pediatric oncology clinic with Nazemi, then to the adult oncology unit for the administration of the treatment plan.

Like many patients receiving intensive cancer therapy, Koontz faced challenges. “I started at 215 pounds and in a month’s time, during

radiation, I went down to 140 pounds,” he says. The use of a feeding tube helped him gain weight back. To address late treatment effects, Koontz benefitted from the services of OHSU endocrinologist Kevin Yuen, M.D., as well as physical and occupational therapists. Koontz feels blessed to have had access to a team of OHSU specialists who provided state-of-the-art treatment and compassionate care. Therapy helped him learn to walk again after brain surgery, and he has progressed from using a wheelchair to walking on his own.

At six years post-treatment, Koontz, 36, is grateful to be in remission. “I still go to physical and occupational therapy and have some disability, but I can’t complain,” he says. For what he’s been through, he feels he has a good life. His film, *Ekimmu: The Dead Lust*, premiered in June 2012 in Portland and was shown again in October. He is currently back to work on a music project.

“At Doernbecher, I was treated awesome, handled great,” Koontz says. “I felt safe, taken care of and had people watching out for me.” Koontz is grateful to his OHSU healthcare team to be living his life and doing the work he loves best.

# Doernbecher Survivorship Program Offers Guidance to Physicians, Patients

Children, adolescents and young adults who have been treated for cancer are at risk of developing chronic medical conditions, known as late effects of treatment. Two-thirds of childhood cancer survivors will develop at least one chronic medical condition; of these, one-third will have a severe or life-threatening condition.

Early detection can prevent many of these conditions or reduce their severity. For this reason, survivors of childhood and young adult cancers need lifelong health screenings specifically directed to late treatment effects.

The Doernbecher Survivorship Program offers comprehensive care and support to any patient who has been treated for a childhood or young adult cancer and has been off treatment at least two years. The program offers patients a summary of their cancer treatment, a personalized plan for future health screenings and survivorship resources for the patient and referring medical team.

## OUR TEAM

The Doernbecher Survivorship Program is led by Susan Lindemulder, M.D., a pediatric hematologist/oncologist with advanced training in clinical research.

Other members of our multidisciplinary team include:

- Oncology nurse practitioner
- Pediatric and medical subspecialists
- Social worker
- Clinical psychologist/ Neuro-psychologist
- Oncology nurse educator
- Educational specialist
- Dentists

The Survivorship Program also has subspecialty clinics for children and adolescents who were treated for brain tumors and require neuro-oncology follow-up.

## HOW THE DOERNBECHER SURVIVORSHIP PROGRAM WORKS

Patients may be referred to the Survivorship Program by Doernbecher physicians or community providers, or may

be self-referred. (Patients may have been treated anywhere; the program is not restricted to patients treated at OHSU.) At the initial visit, patients meet with members of the multidisciplinary team to discuss survivor issues specific to their cancer treatment.

### Before the Survivorship Program visit

When a referral is received, the Survivorship Program coordinator will contact the patient to schedule an initial appointment. This is usually two to three months in the future to allow time to obtain treatment records, verify insurance coverage and coordinate evaluations. If the patient was treated elsewhere, the Doernbecher Survivorship Program will obtain records from the treating institution after getting the patient's consent. These records are used to create the Cancer Treatment Summary.

After the initial contact, the Survivorship Program coordinator will send the patient a questionnaire on his or her current medical condition, educational and vocational status and mental health history. This information and the Cancer Treatment Summary are used to guide the visit.

### During the visit

The team meets with patients on Friday afternoons, but patients are told to prepare to spend the whole day on the OHSU campus. In the morning, patients will typically complete laboratory tests and other evaluations, such as EKGs, echocardiograms and hearing evaluations. In the afternoon, patients meet with the team to review the Cancer Treatment Summary, recommendations for lifelong health screening and the results of the day's evaluations.

### After the visit

After the visit, the survivorship team compiles the Cancer Treatment Summary, test results and screening recommendations in a report that is sent to the patient. The report also goes to the primary care provider and any other provider the patient identifies as part of the medical team. The primary care provider also receives a separate Survivorship Roadmap to help him or her track future screenings.

The survivorship team determines how often the patient needs to be seen based on what late effects they are experiencing.

### SURVIVORSHIP CONSULT SERVICE

Although the Doernbecher Survivorship Program cares for patients who are two years out from treatment, team members are available any time for consultation and questions. Team members offer resources to primary care physicians in the evolving field of cancer survivorship, but do not assume primary responsibility for patient care.

### SURVIVORSHIP EDUCATION FOR PHYSICIANS

The Doernbecher Survivorship Program team is available to educate or speak with physician groups about the unique challenges of cancer survivorship.

### CONTACT THE SURVIVORSHIP PROGRAM

To find out more about the program or to refer a patient, please contact Kitt Swartz, survivorship program coordinator, at **503 494-0200**.

## OHSU Adolescent and Young Adult Oncology Program

Adolescent and young adult brain tumor patients can benefit from the OHSU Knight Cancer Institute's Adolescent and Young Adult Oncology Program. It serves patients aged 15-39 who are being treated for cancer or making the transition to survivorship. OHSU's AYA program, the only one in Oregon, was among the first of its kind in the nation and is considered a model for other institutions looking to better care for this population of patients.

Young adults and teens with cancer have different medical, emotional and social needs from children and older adults. Medical director Brandon Hayes-Lattin, M.D., a survivor of young adult cancer and director of Critical Mass: The Young Adult Cancer Alliance, developed the AYA program to meet these needs.

The AYA program can help with:

- Fertility concerns
- Emotional challenges
- Education, relationships and work re-integration
- Insurance coverage
- Other medical and life issues related to cancer and treatment

Support services include Cancer Transition Sessions, a six-week program to help young adults transition from treatment to survivorship, and Survivor Portland, a support group that meets twice each month. Patients who had a pediatric cancer before age 30 may also benefit from the Survivor Program at OHSU Doernbecher Children's Hospital.

The AYA program works with the following community organizations:

- Familias en Accion
- Oncology Youth Connection
- Athletes for Cancer
- Children's Healing Art Program
- Leukemia-Lymphoma Society
- Candlelighters

Participants in OHSU's AYA program have access to all the resources of the OHSU Knight Cancer Institute, including clinical trials. "Adolescents and young adults are one of the least represented groups on clinical trials," says Susan Lindemulder, M.D., who liaises between the AYA program and Doernbecher's Survivorship Program. "But we now know their biology is different, so it's important for them to be included."

### OHSU ADOLESCENT AND YOUNG ADULT ONCOLOGY PROGRAM TEAM

**Brandon Hayes-Lattin, M.D.**  
Medical Director, AYA Program

**Susan Lindemulder, M.D.**  
Director, Doernbecher Childhood Cancer Survivor Program — AYA Liaison

**Rebecca Block, Ph.D., M.S.W., L.C.S.W.**  
Social Worker and Researcher

**Andrea Lehman, M.S.W.**  
Social Worker, AYA Support Group

**Mindy Buchanan**  
AYA Program Coordinator

Pediatric neuro-oncologist, **Rebecca Loret de Mola, D.O. M.C.R.**, will join the OHSU faculty in August 2013. Her practice focus will be AYA neuro-oncology.

### CONTACT US

To find out more about the program or to refer a patient to the AYA program staff, please call **503 494-0446**.

# Pediatric Brain Tumor Clinical Trials Research

OHSU Doernbecher Children's Hospital makes the latest pediatric brain tumor research available to Oregon and southwest Washington families, including access to clinical trials.

## CHILDREN'S ONCOLOGY GROUP AND COG PHASE I CONSORTIUM

The Children's Oncology Group is a clinical trials consortium of more than 200 hospitals and 7,500 experts worldwide, supported by the National Cancer Institute. It conducts research in children with medulloblastoma, ependymoma, brainstem gliomas, low and high-grade gliomas, germ cell tumors and recurrent CNS tumors. Created in 2002, this limited-institution group has just 21 member institutions nationwide. Members are chosen by peer review. The COG Phase I and Pilot Consortium is a national and international model for pediatric oncology drug development, including expert resources for translational research and advanced imaging. Its primary goals are identifying and developing new and effective therapeutic agents.

**Doernbecher is Oregon's only member of the COG Phase I and Pilot Consortium as well as the only center in Oregon conducting Phase I trials for pediatric cancer care.**

Resources for primary care providers and families include the Late Effects Directory of Services and COG Family Handbook. For more information, visit [www.childrensoncologygroup.com](http://www.childrensoncologygroup.com).

## NATIONWIDE COLLABORATIONS IMPROVE ACCESS TO TRIALS

Patients and providers benefit from OHSU Doernbecher faculty's collaborations with colleagues nationwide. These relationships can help provide quick access to smaller multi-institutional trials. For example, one of the first trials using individual tumor biology to design a treatment plan is "Molecularly Determined Treatment of Children and Young Adults with Newly Diagnosed Diffuse Intrinsic Pontine Gliomas" based at Boston's Dana-Farber Cancer Institute. This trial is open at OHSU Doernbecher. The brain tumor team has a deep and rich network of national colleagues, and difficult cases are often discussed with multiple other experts across the country.

Doernbecher physicians are a resource for Oregon and southwest Washington physicians to connect their patients with the broadest possible range of trials and treatments.

## Doernbecher Joins Cutting-Edge Neuro-Oncology Consortium

OHSU Doernbecher Children's Hospital is a member of the new **Pacific Pediatric Neuro-Oncology Consortium**, a network of leading children's hospitals aiming to improve outcomes for children with brain tumors. The group held its first meeting in December 2011.

Through early phase clinical trials, PNOC will work to understand how brain tumors arise in children and aim to develop personalized treatment strategies for this patient population. The first trials are now being opened. PNOC's mission of testing therapies specific to a patient's tumor biology is well aligned with the OHSU Knight Cancer Institute's focus on personalized medicine.

One of the first PNOC trials will involve creating a vaccine from a patient's tumor cells that is then used to inoculate against recurrence. Doernbecher principal investigators are neuro-oncologist Kellie Nazemi, M.D., director of pediatric neuro-oncology, and neurosurgeon Lissa Baird, M.D.

For more information on PNOC, visit [www.pnoc.us](http://www.pnoc.us) or contact Kellie Nazemi, M.D., director of pediatric neuro-oncology at OHSU Doernbecher and site PI of PNOC, at **503 494-1543** or [nazemik@ohsu.edu](mailto:nazemik@ohsu.edu).



# Medulloblastoma Trials Through Children's Oncology Group

Doernbecher currently has four Children's Oncology Group trials open for medulloblastoma alone. They include:

- **ACNS0331:** A Study Evaluating Limited Target Volume Boost Irradiation and Reduced Dose Craniospinal Radiotherapy 18.00 Gy and Chemotherapy In Children with Newly Diagnosed Standard Risk Medulloblastoma: A Phase III Double Randomized Trial.
- **ACNS0332:** Efficacy of Carboplatin Administered Concomitantly with Radiation and Isotretinoin as a Pro-Apoptotic Agent in Other Than Average Risk (High-Risk) Medulloblastoma/PNET Patients.
- **ACNS0334:** A Phase III Randomized Trial for the Treatment of Newly Diagnosed Supratentorial PNET and High Risk Medulloblastoma in Children < 36 Months Old with Intensive Induction Chemotherapy with Methotrexate Followed by Consolidation with Stem Cell Rescue vs. the Same Therapy without Methotrexate.
- **ACNS0821:** Temozolomide with Irinotecan versus Temozolomide, Irinotecan plus Bevacizumab (NSC# 704865, BB-IND# 7921) for Recurrent/Refractory Medulloblastoma/CNS PNET of Childhood, A COG Randomized Phase II Screening Trial.

To learn more about these trials, visit [www.childrensoncologygroup.org](http://www.childrensoncologygroup.org).

## Bridges Program Improves Comfort and Quality of Life

The Bridges program at OHSU Doernbecher Children's Hospital provides palliative care for children whose brain tumor or other disease may shorten their lives. This form of specialized care focuses on living as fully — and comfortably — as possible.

Started in 2000, Bridges was Oregon's first interdisciplinary palliative care team for children and remains the state's largest. Program Director Kathy Perko, M.S., P.N.P., says, "We give families an opportunity to step back and think about their treatment options." The team works with referring physicians from around Oregon and southwest Washington, as well as with community hospice programs caring for seriously ill children.

The Bridges team has expertise in:

- Pain and symptom management
- Education and counseling
- Spiritual, religious and cultural support
- Sibling, parent and other caregiver relationships

Physicians can refer to Bridges when a patient's health status changes or at any other time services might be helpful. Seeking a palliative care consult does not mean giving up hope, Perko says. "If a tumor is not cured, we hope for different things. We hope a child can spend time with his family or go back to school."

Years of palliative care experience help the Bridges team offer a unique perspective on illness and the end of life. "Most parents don't experience the death of a child more than once," Perko says. "They say, 'What is normal? I've never been through this before.'" Bridges helps families understand and manage their experiences. Perko also happens to have 15 years of experience as a neuro-oncology nurse practitioner, so the depth of her expertise on the matter is unmatched.

Perko recently received the Cambia Health Foundation's Sojourns award for her work with Bridges. She is starting a telehealth program to improve palliative care for families around Oregon. Through sharing resources and keeping in touch, Bridges ensures that Doernbecher supports health care providers, children and families through any outcome.

### BRIDGES PEDIATRIC PALLIATIVE CARE TEAM

|   |  |
|---|--|
| Kathy Perko, M.S., P.N.P.<br>Program Director | Gregory Thomas, M.D.<br>Medical Director |
| Sarah Green, M.D.                             | Windy Stevenson, M.D.                    |
| Bryan Gish, M.S.W.                            | Kenna Conklin                            |

To learn more about Bridges or refer a patient, please contact Kathy Perko, M.S., P.N.P., at **503 494-6201** or [bridges@ohsu.edu](mailto:bridges@ohsu.edu).

## 2011 Analytic Cases — Site and Stage Distribution (All cancers)

| SITE                | MALE        | FEMALE      | TOTAL       | 0          | I          | II         | III        | IV         | UNK       | N/A        |
|---------------------|-------------|-------------|-------------|------------|------------|------------|------------|------------|-----------|------------|
| LIP/ORAL            | 50          | 19          | 69          | 1          | 14         | 14         | 14         | 26         | 0         | 0          |
| PHARYNX             | 81          | 14          | 95          | 2          | 2          | 12         | 14         | 62         | 0         | 3          |
| LARYNX              | 29          | 4           | 33          | 2          | 5          | 6          | 7          | 12         | 1         | 0          |
| NASAL CAVITY/SINUS  | 11          | 9           | 20          | 0          | 1          | 0          | 5          | 7          | 2         | 5          |
| THYROID             | 42          | 76          | 118         | 0          | 65         | 9          | 25         | 15         | 4         | 0          |
| ESOPHAGUS           | 61          | 15          | 76          | 0          | 23         | 13         | 22         | 16         | 2         | 0          |
| STOMACH             | 16          | 22          | 28          | 0          | 8          | 7          | 1          | 6          | 5         | 1          |
| SMALL INTESTINE     | 17          | 12          | 29          | 0          | 2          | 9          | 9          | 9          | 0         | 0          |
| COLON/RECTUM        | 69          | 49          | 118         | 2          | 15         | 32         | 37         | 30         | 1         | 1          |
| LIVER/BILE DUCT     | 115         | 43          | 158         | 0          | 60         | 51         | 17         | 23         | 5         | 2          |
| OTHER DIGESTIVE     | 15          | 18          | 33          | 1          | 5          | 12         | 8          | 6          | 0         | 1          |
| GALLBLADDER         | 5           | 2           | 7           | 0          | 1          | 2          | 1          | 2          | 0         | 1          |
| PANCREAS            | 46          | 43          | 89          | 3          | 11         | 34         | 8          | 29         | 3         | 1          |
| LUNG                | 181         | 127         | 308         | 1          | 64         | 33         | 81         | 119        | 8         | 2          |
| BONE                | 24          | 17          | 41          | 0          | 11         | 12         | 2          | 5          | 0         | 11         |
| SOFT TISSUE         | 66          | 44          | 110         | 0          | 29         | 28         | 35         | 15         | 3         | 0          |
| MELANOMA/SKIN       | 142         | 114         | 256         | 77         | 118        | 38         | 10         | 6          | 7         | 0          |
| BREAST              | 2           | 335         | 337         | 39         | 150        | 99         | 25         | 18         | 4         | 2          |
| CERVIX UTERI        | 0           | 13          | 13          | 0          | 6          | 5          | 0          | 2          | 0         | 0          |
| CORPUS UTERI        | 0           | 48          | 48          | 0          | 24         | 4          | 10         | 4          | 6         | 0          |
| OVARY               | 0           | 36          | 36          | 0          | 12         | 2          | 17         | 4          | 1         | 0          |
| PROSTATE            | 213         | 0           | 213         | 0          | 31         | 126        | 28         | 26         | 2         | 0          |
| OTHER MALE          | 23          | 0           | 23          | 0          | 9          | 3          | 8          | 0          | 0         | 3          |
| KIDNEY/RENAL        | 72          | 45          | 117         | 1          | 49         | 9          | 17         | 26         | 7         | 8          |
| URINARY BLADDER     | 38          | 13          | 51          | 12         | 4          | 10         | 7          | 14         | 2         | 2          |
| BRAIN/CNS           | 154         | 193         | 347         | 0          | 0          | 0          | 0          | 0          | 0         | 347        |
| LYMPHOMA            | 100         | 72          | 172         | 0          | 45         | 34         | 29         | 49         | 4         | 11         |
| LEUKEMIA            | 95          | 72          | 167         | 0          | 0          | 0          | 0          | 0          | 0         | 167        |
| MULTIPLE MYELOMA    | 26          | 28          | 54          | 0          | 0          | 0          | 0          | 0          | 0         | 54         |
| OTHER HEMATOPOIETIC | 29          | 22          | 51          | 0          | 0          | 0          | 0          | 0          | 0         | 51         |
| OTHER SITES         | 67          | 61          | 128         | 0          | 25         | 26         | 10         | 6          | 7         | 54         |
| UNKNOWN PRIMARY     | 17          | 10          | 27          | 0          | 0          | 0          | 0          | 0          | 00        | 27         |
| <b>TOTALS</b>       | <b>1801</b> | <b>1564</b> | <b>3365</b> | <b>141</b> | <b>788</b> | <b>628</b> | <b>446</b> | <b>535</b> | <b>74</b> | <b>753</b> |

Note: Figures above represent 2011 analytic cases only (diagnosed here and/or received part or all first course treatment here). Cases of basal and squamous cell carcinoma of the skin and CIS of the cervix are not collected.

### Quality improvement projects for 2012:

Early in the year, The OHSU Knight Cancer Institute embarked on a telecom linkage project. Special video conferencing equipment was installed, allowing physicians at affiliate hospitals to participate in OHSU specialty tumor board teleconferences, resulting in improved patient care and physician communication.

The Department of Radiation Medicine has executed a portfolio of process improvement

projects and quality initiatives starting more than 18 months ago based on LEAN process improvement concepts. This portfolio included projects focused on reducing patient wait times, increasing clinic capacity, standardizing clinic processes. Patient wait times have recently been reduced by 23% using LEAN techniques. In addition, the department has standardized clinic appointment workflows and achieved an increased level of consistency in clinic.

One surgical oncology clinic set out to reduce patient wait times, which were longer than expected from check-in to departure, as reflected in patient satisfaction scores and patient flow assessments. The clinic was able to identify several contributing factors and after implementing a plan, new and returning patient wait times were both significantly reduced.

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Quality Improvement Specialist

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