On September 26, 2009, 140 patients and their family members gathered along with five Pituitary Tumor Center physicians for the Center’s 1st Annual Pituitary Tumor Patient Education Day, held at the Johns Hopkins Mt. Washington Conference Center. Hopkins faculty members spoke to participants about the latest treatments and research on pituitary disorders, including approaches from the fields of neurosurgery, radiation therapy and endocrinology.

The faculty presentations in the morning were followed by lunch and breakout sessions with each physician, organized by discipline, that offered patients a chance to ask individual questions in a small group setting. “Usually one can see his or her doctor for a few minutes,” said one participant. “But here, [we had] the whole day.” The sense of empowerment in the room was palpable as patients and family members took advantage of unparalleled personal access to world-class Hopkins physicians.

Please stay tuned for further updates about the Pituitary Tumor Center throughout the year, including a date for next year’s Patient Education Day!
Physician Presentations

“This is a team effort and no one doctor has all the expertise in the field. It takes a village. All people here are dedicated to give you the best possible care and to advance the field.”

Henry Brem, MD

“Consistent with Johns Hopkins Medicine's mission, the Pituitary Center strives to set world standards of excellence in the care, research and medical education for disorders of the pituitary. Each of our patients is a unique individual requiring a personalized treatment plan and care.”

Gary Wand, MD

Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9:30-10:30</td>
<td>Registration and breakfast</td>
</tr>
<tr>
<td>10:30-10:35</td>
<td>Welcome (Roberto Salvatori, MD)</td>
</tr>
<tr>
<td>10:35-10:55</td>
<td>Sellar masses and pituitary tumors (Gary Wand, MD)</td>
</tr>
<tr>
<td>11:00-11:20</td>
<td>Surgical therapy of pituitary tumors (Henry Brem, MD)</td>
</tr>
<tr>
<td>11:20-11:40</td>
<td>Images from the operating room (Alfredo Quiñones-Hinojosa, MD)</td>
</tr>
<tr>
<td>11:40-12:00</td>
<td>Medical therapy of pituitary tumors and pituitary failure (Roberto Salvatori, MD)</td>
</tr>
<tr>
<td>12:00-12:20</td>
<td>Radiation therapy for pituitary tumors (Michael Lim, MD)</td>
</tr>
<tr>
<td>12:30-1:30</td>
<td>Lunch</td>
</tr>
<tr>
<td>1:30-3:00</td>
<td>Breakout sessions</td>
</tr>
<tr>
<td></td>
<td>1) Medical therapy (Dr. Wand and Dr. Salvatori)</td>
</tr>
<tr>
<td></td>
<td>2) Surgical therapy (Dr. Quiñones-Hinojosa and Dr. Gallia)</td>
</tr>
<tr>
<td></td>
<td>3) Radiation therapy (Dr. Lim)</td>
</tr>
</tbody>
</table>

Dr. Roberto Salvatori speaks to patients about medical therapy of pituitary tumors.
The 1st Annual Pituitary Tumor Patient Education Day provided a wonderful opportunity for patients to connect with their physicians and to hear about both standard treatments and new developments in the field. “It’s absolutely essential for patients to have knowledge of the kind we got today — very instructive in how we move forward with the tumor and after the surgery,” said one event attendee. “[It’s] highly important for the interaction and flow of information between doctors and patients.”

The Patient Education Day also gave patients a chance to meet others with similar conditions, going through the same treatments. Vanessa Powell describes her struggles to find a support network: “When I found out I had a pituitary tumor, I tried to communicate with other people and I couldn’t find the right people to talk to. This [event] gave me an opportunity to network with the patients who had successful treatments in the past; I exchanged phone numbers and was able to get information and talk to those who went through, or are going through, the same thing as me. Today gave me more confidence to be able to make the right decisions about surgery in the future.”

Patients and their family members left the Patient Education Day with hope for the future.

“I have my life back.”

Grace Garrett proudly shows off her old driver’s license as a record of how far she has come since treatment for Cushing’s disease in 2007.

Ms. Garrett enjoyed hearing about—and seeing—the cutting-edge medical therapies and surgical techniques in use every day at the Pituitary Tumor Center at Johns Hopkins.

“Amazing, very informative, very fascinating [intraoperative] videos. I didn’t expect them or realize all the technology and medication therapies. It left me speechless.”

For another patient perspective, check out Georgina Buchanan’s inspirational story at http://www.holamun2.com/shows/hook-up/the-hook-up-neurosurgeon-alfredo-quinones
Dear Patients and Families,

We are delighted to welcome you and your family to our center. This past year was full of excitement and new discoveries. We welcome you to our first of many updates and newsletters in an attempt to inform you about some of the exciting clinical and research advances in pituitary disease being carried out at the Pituitary Tumor Center at Johns Hopkins. We thank those patients and their families who attended our first annual Pituitary Tumor Patient Education Day, which we hope was informative and helped some to understand potential causes, diagnosis, and treatment options for patients living with pituitary problems.

As you probably know, pituitary tumors are common intracranial tumors. They occur in as many as 10% of adults. Although they are almost invariably benign, they can cause significant health problems, either by compressing the surrounding intracranial structures, or by producing excessive amounts of one or more pituitary hormones, or by damaging the function of the normal pituitary gland. The impact on patients’ lives and their families cannot be properly quantified, and it is this effect in our society that we take very seriously.

We believe that an integrated Pituitary Tumor Center, where the expertise of several physicians involved in the care of pituitary tumors is brought together, is the best way to develop an optimal course of therapy. There are, however, many unanswered questions regarding treatment strategies and the origin of pituitary tumors. Our group is working diligently on several fronts to answer questions that include finding the best diagnosis and treatment course depending on patients’ age and overall health status, the testing of new medications, and the discovery of genetic causes that place some people at higher risk of developing pituitary tumors.

We hope that you will find this first newsletter informative - it will be the first of many more to come in which we will continue to update you, to share our enthusiasm and excitement for our work, and to demonstrate our commitment to improving your quality of life.

With warm wishes,

Roberto Salvatori, MD, Medical Director
Alfredo Quiñones-Hinojosa, MD, Surgical Director
The Pituitary Tumor Center at Johns Hopkins
The pituitary gland is a pea-size gland located behind our eyes and often considered the “master endocrine gland.” It regulates most of the body’s hormonal balance. In particular, it controls the function of the adrenal glands, the thyroid, and the ovaries or testes. In addition, it produces growth hormone (GH) which is necessary for growth during childhood and prolactin which is necessary for milk production after pregnancy and delivery.

The pituitary has two parts. The anterior lobe is the source of prolactin, GH, thyroid-stimulating hormone (TSH, controlling the thyroid), gonadotropin hormones (LH and FSH, controlling testes or ovaries) and adrenocorticotropic hormone (ACTH, controlling the adrenal glands). The posterior lobe contains nerve fibers coming from the brain (hypothalamus) storing oxytocin (necessary for uterine contractions during delivery) and anti-diuretic hormone (necessary to regulate the amount of urine we make).

The most frequent cause of pituitary malfunction is a benign tumor (adenoma) of the gland. Pituitary failure can also occur with pituitary infarction caused by hemorrhage into a pituitary adenoma (apoplexy), or infarction of the gland after a complicated delivery (Sheehan’s syndrome). Radiation therapy involving the pituitary gland and/or the hypothalamus can result in pituitary failure in up to fifty percent of patients at three to five years from radiation therapy. Finally pituitary surgery itself can cause damage of the gland.

Selected Recent Publications


The Pituitary Tumor Center at Johns Hopkins Hospital offers exceptional expertise and integrated, individualized care in the diagnosis and treatment of hypothalamic and pituitary disorders and hypopituitarism. Working as an interdisciplinary team, the Pituitary Tumor Center is comprised of leading specialists from several departments within Johns Hopkins Medicine, including Endocrinology, Neurosurgery, Ophthalmology, Radiation Oncology, Radiology, Otolaryngology, and Pathology.

With more than 20 years of experience in the evaluation and management of patients with pituitary or hypothalamic tumors, Cushing's disease/syndrome, acromegaly, and other neuroendocrine disorders, our team collaborates with one primary goal - to improve the lives of patients through cutting-edge care.

Patients at the Pituitary Tumor Center also benefit from the latest brain tumor research resources at Johns Hopkins, which further allow our specialists to bring treatments to patients faster. Our foundation of working across disciplines to offer the best individualized treatment plans for our patients is truly what sets us apart from other pituitary tumor programs.

■ For more about the Pituitary Tumor Center, visit [http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/pituitary_center/](http://www.hopkinsmedicine.org/neurology_neurosurgery/specialty_areas/pituitary_center/)

■ For more about pituitary tumor outcomes research, visit [http://www.hopkinsmedicine.org/neurology_neurosurgery/research/OutcomesLab/](http://www.hopkinsmedicine.org/neurology_neurosurgery/research/OutcomesLab/)

Questions or concerns? Contact the Pituitary Tumor Center at Johns Hopkins: **(410) 955-4526**

**Alfredo Quiñones-Hinojosa, MD**
4940 Eastern Ave. B121
Baltimore, MD 21224
(410) 550-3367
DrQ@jhmi.edu

**Roberto Salvatori, MD**
1830 E. Monument St.
Suite 333
Baltimore, MD 21287
(410) 955-3921
salvator@jhmi.edu

**Rita Pach, RN, BSN**
1830 E. Monument St.
Suite 333
Baltimore, MD 21287
(410) 955-4526
rgrusfe1@jhmi.edu