

Special Theme Issue: Care Transitions for Young Adults with Special Health Care Needs, Volume II

In the March 2013 issue of *Forum*, we presented volume I on care transitions for young adults with special health care needs (YASHCN) and the significance of aligning pediatric care with adult medicine. In this issue, we discuss important resources for YASHCN related to legal rights, insurance, reproductive health, and cancer survivorship. It has been our pleasure to bring you this important compendium on care for special populations. As always, we welcome your suggestions for future theme issues. Find me at the 2013 SGIM Annual Meeting in Denver this month, and tell me what you'd like to see!

—Priya Radhakrishnan, MD

ANNUAL MEETING UPDATE

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Come Celebrate Generalism!

Darcy Reed, MD, MPH, and David Thomas, MD, MHPE

Drs. Reed and Thomas are SGIM Program Committee chair and co-chair, respectively.

Come join your SGIM colleagues in *Celebrating Generalism* at the Annual Meeting in Denver, Colorado, April 24-27, 2013! We will kick-off the celebration with an opening plenary session featuring the presidential address by Ann Nattinger, MD, MPH, MACP, professor of medicine and chief of general internal medicine at the Medical College of Wisconsin. To celebrate the diversity of scholarship presented at the national meeting, the opening plenary session will also showcase one top-rated submission (by peer review) in each of four submission categories: scientific abstract, innovation in medical education, clinical practice innovation, and clinical vignette.

There was a record-high number of outstanding submissions this year, ensuring that the 2013 annual meeting will be a terrific place to see cutting-edge discovery and innovation in clinical practice, research, education, and policy. We are also extremely honored to have an outstanding group of plenary speakers, including Peterson Lecturer Wayne Riley, MD, MPH, MBA, MACP, president and chief executive officer of Meharry Medical College; Richard Baron, MD, MACP, group director of Seamless Care Models, Center for Medicare and Medicaid Innovations; and Catherine Lucey, MD, vice dean for education at the University of California, San Francisco, School of Medicine.

Check out the preliminary program online (<http://www.sgim.org/meetings/annual-meeting/schedule>). Make the most of your time at the meeting by using the meeting tracks to identify workshops, symposia, updates, abstracts, innovations, and poster sessions in your area of interest. For our students, residents, and fellows, there is a track of help-

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Introducing GIM Connect— Connect.SGIM.org

Julie Machulsky

Ms. Machulsky is SGIM Social Media Manager.

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SGIM is pleased to announce the launch of GIM Connect—a new enhanced membership directory and online collaboration platform. It is the online professional home for the SGIM community and academic general internists. GIM Connect allows members to easily interact and communicate online, forming knowledge communities and sharing resources. Tools such as commenting capabilities and the ability to recommend resources will ensure quick and easy access to the most relevant content.

GIM Connect will officially launch at the annual meeting when all the site's features will be fully integrated. Here's a quick overview of some of the features:

- *All-member forum and additional communities by interest or professional focus (i.e. education, research, clinical practice, hospital medicine, and leadership):* Pose questions, share resources.

- *Member profile pages complete with photos and biographies:* Create your professional profile in the Academic General Internal Medicine community.
- *Enhanced e-mail capabilities:* With GIM Connect, members receive e-mails that are more structured and easier to read. You can also select your subscription frequency.
- *Detailed search results:* With the new platform, you have new ways to search for colleagues and resources.
- *RRS feed:* Now you can select any or all the communities in which you are a member, and they will be aggregated into a single feed.
- *Bookmarking:* Found a useful resource on the site? Add it to your favorites for quick and easy access in the future.
- *Other features:* We also offer blogs, wikis, shared calendars, and more!

We plan to take the site out of beta mode at the opening of the annual meeting. Mobile capability upgrades are in the works as well. GIM Connect will continually evolve to meet the needs of SGIM members. Your online community awaits you. It's time to Connect!

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Advancing Your Career

Ann Nattinger, MD, MPH

Most of us expect to be innovative with our areas of scholarship, but I would argue it is best to introduce innovation into every aspect of our work, including administrative or committee service.



I have been in academic medicine for a couple of decades now and have been a division chief for more than 10 years. In that time, I have observed some strategies that I think help advance one's career. Without pretending that I have always done everything optimally, I offer these general thoughts about career advancement.

Develop a clear vision for each phase of your career, and be sure it is aligned with the organization's priorities. Most of us go through phases in our careers. For example, we may be clinician-teachers at one time, associate program directors or directors of medical student education at another time, and perhaps take an advanced leadership role later in our careers. At each phase, it is important to have a clear sense of what we wish to accomplish. Maintaining the status quo is rarely a good idea, but when we develop our vision for our role, we should be aware of the institution's strategic priorities. If you have a great idea for a laboratory to advance scholarship in medical education, but the institution is working on developing the cancer center, then you may feel like you are up against a brick wall. One may need to scale back or re-orient one's vision to fit the institution. (Can you study medical education related to cancer, for example?) Hopefully this is discerned prior to taking on a new responsibility, and it is related to the idea of a "good fit" for people and positions.

It's OK to bring forward problems, but do so in the context of potential

solutions. Most of our divisions, departments, and medical schools have faculty meetings or other venues for critical faculty discussions. Leaders at these meetings tend to hear a lot of complaints, and most of these externalize the problem outside of the person or group affected. For example, you may feel that your productivity in clinic is diminished due to a lack of resources provided by the hospital. A natural response of the department chair may be to question whether the resources are being used optimally. If you decide to bring this problem forward, have some potential solutions in mind that are not all dependent on doubling your clinic's budget. Perhaps you acknowledge the possibility that the resources are not optimally utilized, for example, and propose comparing to external benchmarks. If you decide to raise the problem, you should be prepared to devote some of your own time to developing the solutions.

Try to introduce innovation into every responsibility you take on. Most of us expect to be innovative with our areas of scholarship, but I would argue it is best to introduce innovation into every aspect of our work, including administrative or committee service. Avoid doing things the same way just because they have always been done that way. Perhaps this is another way of saying to think "outside the box." Studies indicate that creative people address problems by letting their minds wander, allowing free association.¹ This gives rise to innovative "outside the box" ideas. This type of

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thinking takes some time free from the usual hustle and bustle of the day. In academic settings, creativity is typically valued, and being known as a person with innovative ideas (even if they pertain to the library committee) will generally help your career.

Keep your commitments. It is critical to think seriously before taking on new commitments. Some faculty have not learned how to politely and tactfully decline certain opportunities and so become over-committed. What typically follows is an inability to perform some—or worse, all—of one's commitments at or above the expected standard. Be sure that you agree to commitments that you can accomplish and that you can take some gratification in accomplishing them well. You do not want to get a reputation for rarely showing up at meetings, for failing to bring the piece you said you would write, and so on. I realize that it can be difficult at times to discern whether a given

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The Young Adult with Special Health Care Needs and the Internist

Eva Waite, MD, FACP, FAAP

Dr. Waite is an assistant professor of medicine and pediatrics at Mount Sinai School of Medicine.

Due to advances in modern health care, a child born today with a chronic illness such as cystic fibrosis, spina bifida, or sickle cell anemia has a 90% chance of living into adulthood.¹ These young adults with special health care needs (YASHCN) and their families will need to navigate the transition from pediatric to adult-oriented health care. In addition, the internists receiving these patients must also be prepared to take on patients with unfamiliar and uncommon chronic health conditions that are complicated by the social and emotional development of these young patients.

Ideally, transition should occur as a process that involves multiple steps to prepare the YASHCN and not just a simple transfer from a pediatrician to an internist. The 2005-2006 National Survey of Children with Special Health Care Needs defined appropriate transition services as: 1) planning the shift to an adult provider to address future health care needs, 2) encouraging the development of self-management skills, and 3) providing information on insurance maintenance.² In addition, the 2002 consensus statement on transition states that the “knowledge and skills needed to provide developmentally appropriate transition services to YASHCN should be part of the training and certification requirement for primary care residents and physicians in practice.”² What the consensus statement doesn’t specify is what these edu-

cational requirements are and when residents should receive this training. Part of this transition process is the domain of the adult medicine-trained physician, but it is not clear what educational processes have, or should be, put in place.

There is currently no consensus as to when and how training residents regarding transition should be done. There have been a few published surveys trying to elicit educational needs. One survey of eight primary care training programs in South Carolina elicited residents’ preferences for a curriculum on health care transition.³ In this survey, 61% of residents had at least monthly encounters with patients at or near the age of transition. Regarding preferences for types of training in transitions, 79% wanted clinical experience, 60% wanted case-based discussions, and 57% wanted a lecture format. Only 10% of residents preferred a web-based modality. The majority of residents (79%) preferred a continuous curriculum throughout residency as opposed to a particular year of training. In addition, 84% of pediatric residents were open to the idea of rotations with patients outside their scope of training (i.e. adult patients) compared to only 42% of internal medicine (IM) residents. Topics of greatest need/interest included: medical knowledge of pediatric illness persisting into adulthood (77%), identifying resources for YASHCN (57%), discussing end-

of-life issues with young patients and families (56%), and caring for adult patients reliant on caretakers (53%).

A second single-institution survey of IM and pediatric residents revealed that both groups of residents felt that transition should occur at a mean age of 18. However, only 13% of IM residents compared to 78% of pediatric residents had participated in an educational session regarding transition. IM residents were significantly more uncomfortable treating childhood-onset illnesses with the exception of asthma. Discomfort with neurodevelopmental disorders, such as autism spectrum disorders, was particularly striking. There was less of a difference in the level of comfort in treating chronic disease in the outpatient setting between pediatrics and IM residents. However, IM residents did not feel they would be likely to care for patients with autism, cerebral palsy, or spina bifida after completing residency. In response to this discomfort caring for YASHCN, this particular institution created a curriculum to address transition needs involving disease-specific transition presentations, medical school advocacy seminars, and a training program for ancillary health care professionals.⁴

At present, several barriers explain the hesitancy to transition the YASHCN from the pediatric to the adult medical home, including:

1. Pediatric care is more family focused, with parents taking charge of most decision making;
2. Families and patients may be reluctant to let go of an established relationship with a trusted physician;
3. Funding and access to key staff are limited;

...84% of pediatric residents were open to the idea of rotations with patients outside their scope of training (i.e. adult patients) compared to only 42% of internal medicine (IM) residents.

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Addressing Transition of Young Adults with Special Health Care Needs in Non-health Care Domains

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As the population of adolescent and young adults with chronic illnesses and disabilities continues to grow, an increasing emphasis will be placed on enhancing health care transitions from pediatric- to adult-oriented care settings. Greater attention will also be given to the critical role that physicians and other health care providers play in facilitating the transition of these individuals in non-health care domains. Specifically, providers should be aware of existing legislation and available resources that might aid the transition process in the areas of education, vocation, and independent living.

Such a focus is particularly necessary given the relatively poor outcomes of individuals with special health care needs in these domains. Data show that approximately 20% of individuals who have disabilities drop out of high school—more than twice the rate of their non-disabled peers.^{1,2} Similarly, it is estimated that 35% of people with disabilities are working compared to 78% of those without disabilities.¹ Lastly, it has been reported that individuals with disabilities are twice as likely as peers to worry about not being able to care for themselves or being a burden to their families.¹

There has been significant legislation enacted since the early 1970s to address the educational needs of children, adolescents, and young adults with disabilities. Beginning with the Education of All Handicapped Children Act (EAHCA) of 1975 through the Individuals with Disabilities Education Act (IDEA), most recently amended in 2004, Congress has made provisions to enhance the educational opportunities of individuals with disabilities

and assist in their transition to a maximally productive and rewarding adult life.

The EAHCA was instituted to assure free, appropriate public education to disabled children in all states.³ This legislation also established the standard of devising an Individualized Education Program (IEP) for every child receiving special education, with provision of services to extend through age 21. The IEP is developed through collaboration among students, parents, teachers, and administrators to organize school-based educational supports and services with the long-term vocational and professional goals of the student in mind. The IDEA mandates that educational transition planning must begin no later than age 14 and be in action by age 16, with a specific member of the IEP team assuming responsibility for each transition.³ Furthermore, the IEP transition plan must include goals for employment and adult living after high school and attempt to link individual students to community resources and agencies that might foster successful attainment of these goals.

For post-secondary education, the 1990 Americans with Disabilities Act (ADA) legislates that individuals may not be denied admission to post-secondary school based solely on the presence of a disability if they otherwise meet essential admission criteria.⁴ It further mandates that schools provide academic adjustments and supports (such as sign-language interpreters and extended time for testing) appropriate to an individual's disabilities as long as these adjustments do not result in undue financial or administrative burden to an institution.

The role of the physician as defined through this legislation is merely to provide the diagnosis and evaluation of the disability in facilitating access to mandated educational supports. However, the health care provider has an important opportunity to advocate for the patient during this transition process by understanding relevant legislation, being aware of available community resources, and offering guidance when appropriate.

As referenced, young adults with special health care needs (YASHCN) are more likely than their healthier peers to have difficulty finding employment despite the fact that the majority of these individuals would like to work. Although this is attributable in part to physical and developmental limitations resulting from the individual's underlying medical condition, other factors might also contribute. For example, supplemental security income (SSI) has historically restricted employment, thereby discouraging self-reliance through work. To address this, the Centers for Medicare & Medicaid Services created the "Ticket to Work Incentives Improvement Act of 1999," which was enacted to allow patients to work while continuing to receive SSI and associated Medicaid benefits.⁵ Individuals enrolled in the "Ticket to Work" program are encouraged to seek assistance from state-run vocational rehabilitation agencies in the areas of career counseling, vocational training, employment searches, and education regarding self-employment and telecommuting opportunities. Individuals might also be linked with a federally qualified Employment Network (EN) that can aid those with a

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Legal Options, Challenges, and Insights in Supporting Young Adults with Disabilities

Kimberly C. Bates, MD; Cory Ellen Nourie, MSS, MSLP; Christopher Hanks, MD; and Allen Friedland, MD

Dr. Bates is director of the FACES Family HIV Program at Nationwide Children's Hospital and an assistant clinical professor of pediatrics and internal medicine at The Ohio State University College of Medicine; Ms. Nourie is a patient transition social work coordinator at Nemours A.I. duPont Hospital for Children; Dr. Hanks is chief resident of the Internal Medicine Residency Program at Wexner Medical Center at The Ohio State University; and Dr. Friedland is founding medical director and clinical faculty of the Transition Care Practice (TCP) at the Christiana Care Health System.

For some young adults with special health care needs (YASHCN), turning 18 and becoming responsible for their own health management is not a difficult or stressful event because the young adult is competent to make decisions with support, guidance, and insight from his/her parents. These patients are able to make choices and understand the consequences of their actions; however, they may be delayed in their maturity to make informed decisions when compared to their healthy peers.

Other YASHCN, particularly those with intellectual disabilities, have significant hurdles in transitioning to autonomous medical decision making. For many of them, it is difficult—if not impossible—for them to make informed decisions on their own. Formal guardianship offers parents/caregivers the promise of legal protection against financial predators, ill-meaning family members, and adverse outcomes related to failure of adequate self-care. Yet guardianship is also fraught with its own threats to patient autonomy and self-determination. Described by Flynn¹ as the conflict between “best interests” and empowerment, guardianship creates tension between respect for patient autonomy and concern for patient competency, which may be in question depending on the disability. This

article discusses some of the challenges impacting the parent-patient-provider relationship as it relates to guardianship, patient advocacy, and medical decision making in YASHCN.

Parents of YASHCN may be fearful of losing inclusion in the medical decision-making process for their adult children due to concerns about HIPAA (Health Insurance Portability and Accountability Act) privacy laws. After transferring their child's care to an adult provider, parents may want to discuss guardianship options. General internists and family physicians are frequently asked to complete medical evaluations as part of the guardianship process yet are often unaware of the types of guardianship that exist or should be recommended. Additionally, physicians meeting a young adult patient for the first time may be apprehensive about assessing capacity and need for a guardian. Physicians providing care for these patients should understand the guardianship process as well as alternatives to guardianship, including power of attorney, health care power of attorney (HCPOA), representative payee, or conservatorship.

Although each state is different, most offer several levels of guardianship. Full legal guardianship means that the person is incapable of making legally binding decisions and needs

another person(s) to make decisions for him/her in all aspects of life. Limited guardianship is more specific and only concerns a particular area in which a person is deemed incompetent; examples include guardianship of the person (where the guardian makes all day-to-day decisions for the person); guardianship of property (where the guardian makes all financial decisions for the person); emergency, temporary, or provisional guardianship; 90-day health care guardians; or conservators. A parent may obtain guardianship over finances for an adult child with high functioning autism while still preserving the autonomy of the adult to make his/her own decisions regarding health care and housing. Limited guardianships may be adjusted based on changes in the level of function and can be expanded to cover additional areas as further deficits arise. A combination of different less restrictive options may be required in order to provide the best assistance.²

The legal guardianship process involves filing paperwork in the court system (Orphans Court, Court of Chancery, or Family Court, depending on the state), having the alleged disabled person's capacity and competence assessed by an attorney, and completing a hearing before a judge or magistrate. The process may take several months, and out-of-pocket expenses can range from several hundred to several thousand dollars for families in states requiring a private attorney to file for guardianship. Support in understanding guardianship options can be obtained from several sources, including a local chapter of “The Arc” (www.thearc.org), local

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The HCPOA preserves patient autonomy and decision-making capacity and is a revocable document, so as the young adult patient matures, he/she can revoke his/her parents as the agent or create a new HCPOA, assigning a spouse or partner the role.

Reproductive Health in Transitional Care: Do Ask, Do Tell

Amy L. Burke, MD, MPH, and Michael J. Donnelly, MD

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While most internists are adept at discussing general reproductive health, many are less comfortable when young adults with special health care needs (YASHCN) are involved. The multitude of psychosocial concerns raised by individuals with special health care needs is a daunting challenge for any internist assuming primary care, notwithstanding the disease-specific medical issues. This article broadly addresses psychosocial and medical concerns with regard to reproductive health among YASHCN.

One review article on transition of care suggests that the optimal timing for transition from pediatric to adult providers is *after* patients can demonstrate comprehension of the following:

- The effect of pregnancy on their own well-being;
- The effect of their medications on fertility;
- Any potential teratogenicity of their medications;
- Genetic risk of their disease recurrence in future offspring; and
- Their own increased susceptibility for sexually transmitted disease.¹

The reality is that even among cognitively intact patients with special health care needs, the emotional maturation necessary to comprehend these consequences can be delayed. Parents often vigilantly micromanage their child's medical care. While this may lead to better medical outcomes, it can impair emotional development and the ability to appreciate potential sequelae of sexual activity.

Interestingly, adolescents (age 16 to 20) with congenital heart disease (CHD) are actually less likely to be sexually active than their healthy peers perhaps due to delays in psy-

chosocial development. Those engaging in sexual behaviors, however, are more likely to be involved in higher-risk activity, including the use of drugs and alcohol prior to sex and unreliable contraceptive use.² This may be driven by the belief that they are infertile or a lack of information about the risks of sexual activity.

A recent report on the status of new HIV infections in the United States highlights the importance of access to quality transitional care for young adults with HIV. Youths age 13 to 24 currently comprise 25.7% of new HIV cases despite low screening rates;³ 72% of these new cases were attributed to male-to-male sexual contact. The psychosocial concerns for patients with behaviorally acquired HIV differ from those infected perinatally. Both groups need counseling about how to disclose their condition to partners and how to prevent transmission. Frank discussion about sexual practices, condom use, and access to barrier protection is of paramount importance to all patients at high risk for sexually transmitted infection (STI) or HIV. Teens and young adults with special health care needs may have difficulty engaging in these difficult discussions.

Complex physical health risks exist among medically ill patients. Pregnancy may be life-threatening in conditions such as advanced cystic fibrosis or severe CHD. Physicians must fully counsel these women regarding the dangers to themselves as well as the risks to the fetus. On the other hand, infertility may be a consequence of some conditions or treatments, especially chemotherapy. Providers must assess this likelihood when assuming care.

Managing medications is a particularly vexing problem for some transitional patients. Patients with

autoimmune disease or transplants may not tolerate modifications to their teratogenic medications during pregnancy. Those with cyanotic CHD, right-to-left shunts, and pulmonary vascular disease have increased thromboembolic risk and thus cannot take estrogen.³ Transgendered youth must find adult providers willing to prescribe the hormones necessary to maintain their gender identity. The risk of drug-drug interaction is omnipresent with some anti-seizure and immunosuppressant medications as well.

Additional concerns arise when considering the reproductive health needs of individuals with cognitive impairment. This includes young adults with developmental disabilities like Down syndrome, autism, and countless other genetic, neurologic, or metabolic disorders impacting cognition. Most youth with intellectual disability are mildly impaired with an IQ in the 50 to 75 range. Their interest in sexual activity matches their nondisabled peers, but they may be less aware of how to pursue appropriate relationships. Despite the need for more counseling than cognitively intact peers, they tend to receive less education. The fact that these individuals are often aware of their differences adversely impacts self esteem. This can lead both genders—but particularly young women—to increased promiscuity in an attempt to prove normal femininity.

Additionally, parents and caregivers may be fearful about vulnerability to sexual abuse and risks of STI, thus avoiding the topic. Physicians need to provide access to information and specific guidance about what sexual activity may be appropriate. Many medical institutions prioritize the teaching of barrier
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Providing Adult Medical Care for Childhood Cancer Survivors

Chad K. Brands, MD, and David E. DeLaet, MD, MPH

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In the middle of the 20th century, pediatric hematologists and oncologists exercised scientific investigative genius when setting up their subspecialty field and academic medicine health care infrastructure to serve children with cancer. Large multicenter patient registries were established to study the effects of regimens of chemotherapy and radiotherapy being used to treat childhood cancer. These registries promoted the development of research in the new field, enabling physician investigators to conduct multicenter randomized controlled treatment trials for infants, children, and adolescents. Six decades later, thousands of lives have been saved, and the adverse effects of chemotherapy and radiotherapy are increasingly well known to clinicians treating pediatric or adolescent patients presenting with common and rare malignancies. In addition, the pediatric hematology-oncology specialty has also demonstrated great vision in establishing data registries to study the late effects of childhood cancer. The research from these long-term follow-up registries and studies continues to inform practices for those receiving initial treatment as well as those surviving well into adulthood.¹

Nearly 12 million cancer survivors are alive in the United States, and nearly one third of a million patients were initially diagnosed under age 21.¹ Seventy thousand adolescents and young adults between age 15 and 39 are diagnosed with cancer

each year in the United States.² Given these population demographics for childhood cancer survivors (CCS) and their adult medical care needs, today's general internist must become familiar with the late effects of childhood cancer and its treatment. These effects continue to be studied and reported in the medical literature as investigators continue to follow cohorts of CCS. The discipline of survivor care will continue to mature as survivor clinics expand worldwide.

It is clear that the general internist of the future will be the quarterback of the medical home team.³ In this role, the generalist will need to ensure that CCS receive the evidence-based care that they require following treatment for childhood cancer by using an interdisciplinary approach. This leadership role within the medical home and medical neighborhood includes aspects of primary and secondary prevention, chronic disease management, risk assessment and modification, and interdisciplinary team management applied to the understanding of late effects of childhood cancer.

CCS are at risk for the development of secondary conditions resulting from the treatment of their childhood malignancies. These late effects can include essentially any organ-system depending not only on the extent of anatomic involvement of the initial disease but also the treatment modalities employed in effecting a cure, including but not limited to chemotherapy, radiation therapy,

bone-marrow/stem-cell transplant, and surgical resection. Although a comprehensive review of these effects is well beyond the scope of this article, it is important to note that comprehensive resource guides are available that can help direct providers in the care of CCS and the long-term monitoring for these conditions.⁴

To facilitate optimal patient care in the context of a medical home that utilizes an interdisciplinary approach to wellness and illness, the general internist caring for CCS should follow several critical steps.

Review several key sources of important information on childhood cancer survivors. Although the care of CCS presents many challenges to the adult generalist, considerable resources are available to help guide the care of these individuals. The Childhood Cancer Survivor Study (CCSS) is a retrospective cohort study funded by the National Cancer Institute that includes children diagnosed between 1970 and 1986 and continues to illuminate the field.¹ Similarly, the National Cancer Institute maintains online resources providing information on adolescents and young adults who have survived cancer.² The Institute of Medicine has published a consensus report that focuses on improving the care and quality of life for CCS.⁵ Finally, the Children's Oncology Group (COG) has prepared for health care providers the aforementioned specific guidelines for the long-term follow up of CCS.⁴

Reach out to the patient's pediatric hematology-oncology team for a treatment summary. As recommended by expert panels, a portable medical summary should be established and updated annually by the pediatric medical home provider of all adolescents and young adults with special health care needs.⁶ For CCS, this document should summarize the patient's course

Many survivor clinics now combine the expertise of pediatric hematology-oncology, nursing, psychology, social work, and consultative subspecialty providers from pediatric and adult medicine.

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Insurance Problems of Young Adults Solved by the Affordable Care Act! Or Were They?

Sophia Jan, MD, MSHP, and Santi KM Bhagat, MD, MPH

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The Patient Protection and Affordable Care Act (PPACA) addressed the major issue of insurance coverage for young adults, the largest demographic of uninsured individuals. But for the significant numbers of young adults with special health care needs (YASHCN), the expanded coverage of the PPACA falls short of addressing problems around continuity of insurance, cuts in covered Medicaid services at age 18, inadequacy of coverage for transition and self-management visits, and incongruent provider networks while transferring care across systems. This article attempts to address some of these remaining challenges.

About 9.5 million young adults age 18 to 29, or one in five, has a pediatric-onset chronic medical condition or disability.¹ Until the recent passage of the PPACA, many young adults, including those with chronic conditions and disabilities, became uninsured once they turned 19 either because they aged out of their parents' insurance plans or because they no longer qualified for public insurance. In Ohio, nearly 33% of YASHCN (age 19 to 26) did not have insurance compared to only 5% of children.²

When the PPACA was signed in 2010, private insurers were required to allow qualifying young adults up to age 26 to remain on their parents' insurance plans. This resulted in coverage for an additional 6.6 million young adults who would not otherwise have been covered in 2011.³ Those with pre-existing conditions who were uninsured for more than six months became eligible to apply for insurance through temporary national high-risk pools. The more comprehensive coverage provisions of the law that will benefit young adults will go into effect in

2014. First, health plans will no longer be able to deny or drop coverage for people with pre-existing conditions. Second, Medicaid eligibility will be expanded to 133% of the federal poverty level (FPL) for all individuals under age 65. Finally, young adults whose employers do not offer insurance will be able to purchase insurance through regulated state-based health insurance exchanges with premium and cost-sharing subsidies for those who qualify. Starting in 2019, Medicaid will also be available to all former foster children up to age 25 who were in foster care for more than six months.⁴

However, the PPACA does not address many other critical issues related to the continuity and adequacy of insurance coverage, particularly when transitioning across health systems. First, YASHCN are particularly sensitive to disruptions in insurance coverage. The PPACA's incremental approach to near-universal coverage has raised concerns that changes in income, employment, and family composition—which is the norm for adolescents and young adults—will shift young people into and out of different coverage arrangements over time, a phenomenon known as “churning.”⁵ Furthermore, young adult students with chronic conditions and disabilities may have difficulty maintaining school-based insurance since they are more likely to enroll part time and experience disruptions in attendance due to their illnesses. To address concerns about churning among low-income adults, some states are considering adopting a Basic Health Program (BHP) option of the PPACA. Under this option, states would receive a lump-sum payment equal to the cost of insur-

ance exchange subsidies for households with incomes between the Medicaid cutoff and 200% of the FPL. The state would then assume responsibility for financing a BHP that contracts with Medicaid plans and providers to reduce coverage disruptions for low-income adults up to 200% of the FPL whose incomes rise or fall across Medicaid income eligibility over time.

Finding adequate insurance is also difficult for YASHCN. Medicaid is required to cover all medically necessary services and prohibits cost-sharing for children under age 18 because of rules under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. But when children turn 18, many of these services—including prescription drugs, dental care, durable medical equipment, and personal care services—become “optional” Medicaid-covered services that vary from state to state. Standard commercial insurance plans typically cover fewer of these services. As part of the PPACA, the Department of Health and Human Services has defined a set of 10 categories to be included in essential health benefits of all private and public plans, which now includes mental health services, prescription drugs, chronic disease management, and rehabilitative services and devices. Exactly what specific benefits states will include under these broad categories is still unknown. But for YASHCN, inadequate coverage exacerbates their inherent heightened risk of secondary mental or physical health conditions.

For YASHCN, the greatest risk in becoming an adult is not financial in nature. Rather, it is the threat of institutionalization or of having basic

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4. Transportation, legal services, social services, and vocational services are all needed in the course of care; and
5. Internists may feel uncomfortable treating diseases that are unfamiliar to them.

Internists are generally the group of providers most often charged with caring for patients with chronic medical illnesses. The main difficulty in caring for YASHCN is recognizing the intellectual and emotional challenges of these patients. Although internists have some familiarity with shared decision making in the care of elderly or demented patients, they may struggle to recognize these barriers in younger patients. Many YASHCN have intellectual and or developmental issues due to the underlying disease (sickle cell, autism) or sequelae of disease treatment (cancer, transplant). They often have lower levels of educational attainment and health literacy due to their chronic disease. Internists have to be prepared to recognize these limitations and adjust their patterns of care. YASHCN may not yet have developed self-management skills and often have to develop these skills while transitioning to the adult provider. These young adults may need help in developing communication skills, advocating for themselves, and making decisions.

YASHCN often have legal and insurance barriers that first manifest themselves at the age of transition. Current changes in health care law now allow these young adults to remain on parental insurance until age 26, but adult care providers will need to be prepared to help these patients retain medical coverage. Maintaining insurance status is often critical to achieving optimal health but made difficult by the fact that many YASHCN are not employed and are reliant on public insurance (Medicaid and Medicare). Eligibility requirements become more stringent for adults and make this an additional hurdle internists must become familiar with to aid these patients. Some

YASHCN will also need to have legal clarification of their ability to consent for both medical and legal decisions. Although this is ideally done before age 21, it is often neglected and may need to be addressed by the adult health care provider.

One survey of adult sub-specialists attempted to identify the specific knowledge gaps and barriers to accepting YASHCN into their practices.⁵ A 2008 survey of adult gastroenterologists reported that 55% of young adults with inflammatory bowel disease had deficits in knowledge of their own medical history and that 69% did not know the medications they were taking. Additionally, 51% of adult providers received an inadequate medical history from the pediatric provider. This survey also indicated that adult sub-specialty providers were less concerned about the YASHCN ability to identify previous providers (19%) or attend office visits by themselves (15%). Respondents believed that knowledge of adolescent medical and developmental issues was important, but only 46% felt competent addressing developmental concerns.⁵ Surprisingly, physicians in practice for less than five years reported more problems with transition issues than their peers further out from training.

These studies highlight the importance of the pediatrician readying the YASHCN for the transition by educating the patient regarding the chronic condition and assessing legal and medical capacity. Adult providers and families were less concerned regarding the initial need for family- vs. individual-centered care and decision making. All studies recognized the need for ongoing medical education of the adult providers regarding the needs of these patients as they transition to adult care. One of the responses to this need is an ongoing series published by the American Academy of Pediatrics (AAP) that includes articles on the transition of patients with specific chronic disease (e.g. sickle cell, cystic fibrosis, diabetes mellitus, and abuse) to internists.⁶⁻¹⁰

The next challenge will be getting this knowledge into the adult/IM literature. Training curricula must be developed for students, residents, and fellows to provide primary and specialty care for this growing group of patients.

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disability in developing an individual work plan that outlines the individual's employment goals and the ways in which the EN can provide assistance. These agencies can be linked to children with developmental disabilities during the annual review of the IEP transition plan at school. Additionally, to further support the transition of YASHCN, it is imperative that providers collaborate early in the transition process with social work service providers who are familiar with these programs and can provide support to these individuals and their families as they consider future vocational goals.

YASHCN are likely to face many challenges as they attempt to transition to independent living. In part due to physical and intellectual impairments, these young adults may be unable to live safely and comfortably without the assistance of others. Limitations in income and options for transportation may additionally result in continued dependence on family members. In turn, family members are more likely to suffer financial hardship, thereby restricting available resources for on-going support. Given these obstacles, individuals should be aware of legislation and resources that facilitate independent living. As concerns financial assistance, patients and their families should inquire early in the planning process about their eligibility for SSI and Social Security disability insurance, realizing that eligibility standards for adults are not identical to those for children younger than age 18. In regard to housing, the Fair Housing Act of 1968 prohibits discrimination in the sale, rental, and financing of dwellings and other housing-related transactions based on the presence of a disability.⁶ Additionally, the ADA has provisions that allow for individuals, at their own cost, to make reasonable structural modifications to units and public common areas in a dwelling when those modifications may be necessary for a person with a disability to have full enjoyment of a dwelling.⁷ When

necessary, referral to a legal expert to assist in the application of such legal rights may be helpful in achieving independent living. Individuals should also consider consultation with their local Center for Independent Living, which is a community-based, non-residential non-profit agency designed and operated by individuals with disabilities to assist others with disabilities in independent living skills training, peer counseling, and provision of information and referral services.⁸ Early collaboration with social work service providers who are familiar with such legislation and community services is critical in all domains. Social work service providers may also be able to assist patients and their families in determining eligibility for a home-health attendant or homemaker services, adaptive medical equipment, assistive technology, family respite services, and transportation services.

In planning for the transition of YASHCN, health care providers need to consider both health care and non-health care domains. The challenges of transition can be very stressful to patients and their families. By addressing these challenges early in the process, engaging in on-going discussions about long-term goals for education, vocation, and independent living, and collaborating with social work service providers, legal health experts, and relevant community agencies, health care providers can promote a medically safe transition of care in all aspects of life.

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PRESIDENT'S COLUMN

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opportunity should be accepted or declined, and you may need to seek advice. But if you agree to take on a commitment, you should do it well.

Keep your cool. No matter how good the institution or how good your position's fit, things will inevitably go wrong in the course of a career. Someone will fail to keep their commitment to you, have selective memory about the commitment, or otherwise pull the rug out from under you. At these times, it is important not to overreact—at least in the short term. I think there is a skill from raising teenagers that applies here. You may need to express disappointment and have a difficult conversation. Maybe you will even decide to leave the institution. But don't do any of these while you are in the immediate period of feeling angry or hurt. Losing your temper can be the one thing people remember about you and can harm your ability to influence others. You might need to say you will think about the issue in order to give yourself the needed time to decide (perhaps with advice from a mentor) on the best response. By the time you deliver the response you should be cool and reasoned.

Continue to seek training as your career progresses. Those of us who are clinicians expect to obtain continued clinical training over time, but career development applies to other aspects of your professional life as well. While we can often develop ourselves by observing role models and others at our institutions, it is very useful to gain outside perspectives, whether on new ways of organizing medical education, new methods for research, or leadership training. While general internal medicine faculty typically feel very busy, it is important to take some time during your career to learn about new perspectives and ways of doing things. Many of our members attend the SGIM annual meeting regularly, but I hope that our members will regularly attend sessions that are out of their comfort zone. Even if these do not result in immediate changes in

your life, the broadening experience will likely help you at some point.

Have fun—at least most days! You have worked hard to get here. No one has a great day every day, but you should feel happy to come to work most of the time. If not, you should meet with your mentors, figure out what is wrong, and problem-solve to fix it. One of the many wonderful things about a career in GIM is that there are so many potential career paths. If one pathway isn't working, chances are another will. Sometimes we feel locked into a pathway that we started for whatever reason, but it doesn't need to be that way. I have seen people change into and out of research, education, and administration. It may take strategic planning over some months, but don't be afraid to make a change if you sense that is what you need.

This is my last SGIM *Forum* column as president of SGIM. Before I sign off, let me say how fortunate we are as a Society to have such a wonderful staff. Our SGIM staff members interact with members mostly by phone and e-mail, except at our national conference and a few key meetings that happen throughout the year. It is amazing how engaged they are on our behalf. We are a very participatory Society, which means that our staff stay busy helping to support our various groups (e.g. Council, committees, and task forces); managing our publications, communications, awards, and elections; helping us secure grants; supporting our national and regional meetings as well as special events like the Academic Hospitalist Academy; managing our finances and records; and helping us work cooperatively with other organizations to leverage our influence. Having been privileged to work closely with our staff this year, I am proud of the work they do, and I hope that our members are as well.

I remain so grateful to the SGIM members for giving me this outstanding opportunity to serve our Society as president!

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SGIM

ANNUAL MEETING UPDATE

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ful sessions, including "Pathways to Careers in Academic Internal Medicine" and "Negotiating Your first Dream Job."

We are pleased to announce a new type of session this year, the "VignDate." SGIM meeting attendees have told us that they would like to see more core clinical content at the meeting, so we've created the VignDate—a combination of clinical vignettes and clinical updates. VignDate sessions will include five clinical vignettes that share a common feature, followed by a short clinical update on the topic by a master clinician. We hope this will be an engaging way for attendees to share vignettes and review core clinical content within the same session.

Working on Maintenance of Certification (MOC)? The annual meeting can help. Sign up for American Board of Internal Medicine MOC modules on Wednesday, April 24. Review core material, and get MOC points.

If you're like us, a highly valued aspect of the annual meeting is the opportunity to network with colleagues, meet new people, and catch up with friends. Great venues for this include the one-on-one mentoring program (as mentor or mentee), SGIM's numerous interest groups, the mentoring and career development panels (including the second annual "parenting panel," which is back by popular demand), and the guided poster sessions. Be sure to also take advantage of designated "networking space" set aside throughout the meeting just for this purpose.

See you at the Celebration!

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and state agencies for developmental disabilities, or from the National Health Care Transition Center (gottransition.org).

A HCPOA is an appointed agent(s) directed by the adult patient to make medical decisions on his/her behalf if he/she becomes incapacitated. Many states also allow the patient to authorize his/her agent(s) to access medical records and speak with physicians directly and independently via the HCPOA without needing a separate release of information for each encounter. The HCPOA preserves patient autonomy and decision-making capacity and is a revocable document, so as the young adult patient matures, he/she can revoke his/her parents as the agent or create a new HCPOA, assigning a spouse or partner the role. A HCPOA template is available online for no cost (<http://www.caringinfo.org/l4a/pages/index.cfm?pageid=3289>). Although attorneys may draft documents for a fee, attorney involvement is not required for a valid HCPOA.

Young adults with intellectual disabilities are likely to have legal guardianship in place at the time of transfer. Family caregivers of these young adults may opt for more restrictive guardianship options, despite evidence noted by Gooding showing that many have the cognitive capacity to exercise choice, particularly when given assistance from advocates.³ The concept of shared decision making as noted by Gooding allows patients with intellectual disability to have support for making health care decisions as warranted by the nature of the issue but allows the decision to ultimately rest with the patient if appropriate. Supported decision making is similar to shared decision making in that both place the patient in the center of the decision-making process. In shared decision making, physicians and patients use decision support models and other tools to work together to decide between alternatives. With supported decision making, as described by the United Nations Committee on the Rights of Persons with Disability, the “individ-

ual is the decision maker; the support person(s) explain(s) the issues, when necessary, and interpret(s) the signs and preference of the individual.”⁴ Thus, supported decision making is a form of shared decision making utilizing the guardian as an additional support tool. In addition, physicians can help guardians recognize the best times to assist with a decision and when the patient should exercise decision making. Utilizing a guardian in supported decision making can help the young adult with intellectual disability develop medical management skills within his/her cognitive level.

Physicians can support YASHCN to be self-advocates and medical decision makers as their cognition allows. In situations where this is not possible, physicians can guide families and caregivers to choose options and navigate the formal legal processes involved in guardianship.

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health and daily living needs unmet if they remain in the community without personal care or other home health services.⁶ Despite recent policy changes that have expanded eligibility for these supports in the home and in community-based settings, access to these services is effectively limited by increasingly long waitlists. Promising options and state incentives exist within the PPACA to help address this problem: the Medicaid “Money Follows the Person” Rebalancing Demonstration Program, a state Medicaid option to provide home and community-based services for eligible individuals; the Community First Choice Option to provide community-based attendant supports and services to individuals with disabilities who require an institutional level of care; and a state balancing incentive program to increase the proportion of non-institutionally based long-term care services. While these options can help to address the chief risks of young adults with severe physical and mental disabilities as they turn 18, the extent to which states will choose to include these options in their state plans is unknown.

For medically complex patients followed by multiple specialists who are transitioning from pediatric to adult health care systems (assuming that adult primary care and specialist providers can be identified), their insurance plans may not be accepted by both pediatric and adult health systems concurrently. The incongruent provider networks may lead to interruptions in care, poor care coordination across systems, and poor provider-to-provider communication or subsequent collaboration. To help improve continuity of care among transitioning patients, some states—including Pennsylvania—have permitted eligible adolescent and young adult patients in capitated Medicaid plans to see both pediatric and adult primary care providers within a specified period. Other PPACA-funded health system performance initia-

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NEW PERSPECTIVES

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of medical treatment, including study protocols with chemotherapy and radiotherapy doses, surgeries and procedures, adverse acute effects of therapy, identification and risk of late effects, and health care professionals involved in the patient's interdisciplinary care. The post-treatment roadmap will outline medical care after the cancer treatment protocol has ended. A number of treatment summary formats have been proposed, implemented, and disseminated to facilitate transitions of care.

Consult the interdisciplinary team at your local/regional CCS clinic. Survivor clinics are more than transitional care clinics following treatment for cancer. These clinics follow protocols for care developed by organizations such as the COG that follow treatment on specific investigational protocols. The team monitors for symptoms or signs of late effects and prepares a summary useful to primary care providers. Many survivor clinics now combine the expertise of pediatric hematology-oncology, nursing, psychology, social work, and consultative subspecialty providers from pediatric and adult medicine.

Work with the patient on primary and secondary preventive strategies. Cancer survivors are not immune to the risks for obesity, heart disease, diabetes, and hypertension. In fact, some survivors will have higher risks for the development of these diseases acquired in young adulthood, mid-life, and beyond. If the internist identifies chronic diseases, CCS and their families will be very accustomed to working with an interdisciplinary team of health care professionals to improve their health, well-being, and quality of life. Providers should also remain vigilant for the previously described late effects of childhood cancer, particularly those most commonly associated with the individual patient's primary malignancy and treatment modalities.

When symptoms are reported and/or signs are detected, seek subspecialty consultative expertise while tapping your own subspecialty knowledge as a general internist.

You can commit to promoting the health of the patient within the medical home you lead with your interdisciplinary team. The growing population of CCS is depending on you to provide key components of their adult medical care.

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tives, such as accountable care organizations, medical home demonstration projects, and the community-based Collaborative Care Network Program, have potential to decrease fragmentation of care for medically complex patients if they are carefully designed.

Finally, the PPACA mandated enhanced collection and reporting of data on a number of populations affected by health disparities, notably access and treatment data for people with disabilities. Coupled with the PPACA-formed Patient Center for Outcomes Research Institute, we have a unique opportunity to expand studies on the needs of young adults with chronic conditions and disabilities as they transition from pediatric to adult-centered systems.

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COMMENTARY

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methods for both cognitively and physically impaired sexually active individuals in order to prevent HIV and STIs as well. Frank discussion about sexual issues and safety is just as vital as it is in healthy adolescents.

Caregivers frequently desire menstrual suppression for young women with more severe developmental delays. Some parents seek to regulate their daughters' cycles because they note subtle perimenstrual changes in behavior that suggest discomfort, such as increased irritability or poor appetite. No data document improvement in these symptoms by hormonal suppression, but it can alleviate distress created when women cannot understand what is happening to their bodies or the practical concerns related to caregiver burden on hygiene or unintended pregnancy.

Options to achieve decreased menstruation include various delivery systems of progesterone, estrogen/progesterone combinations, or intrauterine devices (IUDs). Permanent surgical treatments are generally not appropriate first-line treatments in young women with mental or physical disabilities.

Depo-medroxyprogesterone acetate (DPMA) is widely used due to its ease of administration and high amenorrhea rates (50% at one year). Furthermore, it does not interact with anti-epileptic drugs or antibiotics and is typically safe when estrogen is contraindicated. Caveats include breakthrough bleeding, weight gain, and bone loss. Some experts suggest

titrating DPMA (off-label use) every four to six weeks for three cycles to attain amenorrhea more quickly. Studies in healthy adolescents suggest that thinner women are less prone to the 10 to 20 kg weight gain seen in heavier women. DPMA in adolescents lowers bone mineral density when non-users are still gaining bone mass, but this is at least partially reversible. Problematically, treatment in these patients tends to be longer term, and whether this increases fracture risk is unknown.

Combined oral contraceptive pills (OCPs) can be used for extended cycling, leading to endometrial atrophy and lighter periods. There is a paucity of data on use in developmentally delayed individuals, but breakthrough bleeding patterns appear to be similar to initiation of DMPA. While conventional use calls for quarterly withdrawal bleeds, some experts advocate off-label six- or 12-month cycles, making use more palatable for menstrual suppression.

The transdermal patch can be used to achieve extended cycling and may be easier to administer than other methods. Concerns include decreased efficacy in obese patients and potentially increased thromboembolic risk.

Levonorgestrel secreting IUDs are another option for selected patients. Plasma levels of levonorgestrel are low compared with OCPs, and 44% of women are amenorrheic at one year. There has been reluctance to use this method due to concern for uterine perfora-

tion, especially in patients unable to relate abdominal complaints. This is a rare side effect, and use in the developmentally delayed population warrants further study. One downside is that anesthesia is typically required during device placement.

Clearly no single approach works given the diversity of patients who transition to adult care. It is most important to recognize the need for frank discussions about reproductive health and to provide appropriate counselling in this population.

Editor's Note: The views and opinions of authors expressed herein do not necessarily state or reflect those of Medstar Georgetown University Hospital.

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Baystate Medical Center, the Western Campus of Tufts University School of Medicine in western Massachusetts, seeks a progressive clinician/ educator to serve as Chief, Division of General Medicine. The Chief will provide leadership and oversight of the academic enterprise of our three Community Health Centers along with the professional development of faculty within the Division of General Medicine.

The Chief will engage and partner with outpatient primary care physicians to ensure best practices are utilized throughout the health system, while encouraging innovation and mentoring faculty in the advancement of their careers through increased scholarship. The Chief is also responsible for the scholarly activity of 66 Internal Medicine Residents and 32 Medicine/ Pediatric Residents and the academic productivity and stature of the Department of Medicine along with the oversight of the academic and professional development of the Academic Hospitalists.

Please visit our website to learn more or contact:

Frank Gallagher, Senior Physician Recruiter, Baystate Health
at 413-794-2623, or email
Frank.Gallagher@BaystateHealth.org

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**Baystate
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The Western Campus of Tufts
University School of Medicine