

ULMAN CANCER FUND FOR YOUNG ADULTS

Brock Yetso

Executive Director

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What You're In For...

- **A young adult story - “Falling Through the Cracks 101”**
- **The AYA view from the Ulman Cancer Fund for Young Adults**
- **How we're addressing these challenges**

B.C. (*before cancer)



*“Life was grand,
college student, varsity
soccer player until...I
turned 19! The horror!”*

How did he get here?

- At age 19, he started having pains in his chest and trouble breathing while training for pre-season soccer
- Several months, several doctors, a trainer, soccer coach, physical therapist and numerous times trying to convince medical professionals something was wrong...
- Chondrosarcoma – tumor the size of a golf ball found between ribs and lungs

“Real life” to “Cancer life”

- Doctors didn't trust him. He didn't trust them.
- He had to deal with things that no one his age knew anything about. College student & Cancer!
- Attended support group where everyone was his grandparents' age.
- All materials, support and resources were geared to those very nice old people.
- He met very few young adults in the months immediately following his diagnosis.

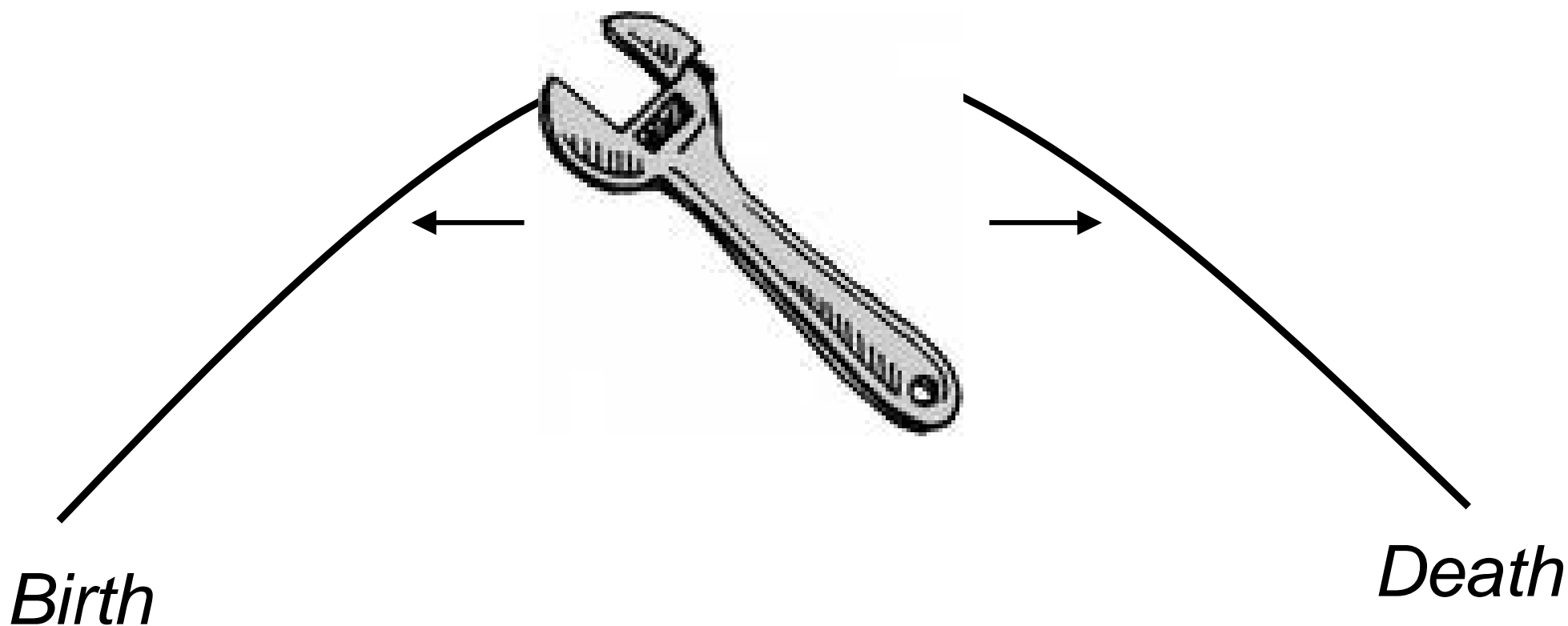
AYA Patient Perspective

- Mistrust (on both sides)
- Steep learning curve with lots of “firsts”
- Isolation; no “home”
- Dropped off a cliff when it’s all over
- Lack of relevant resources and information

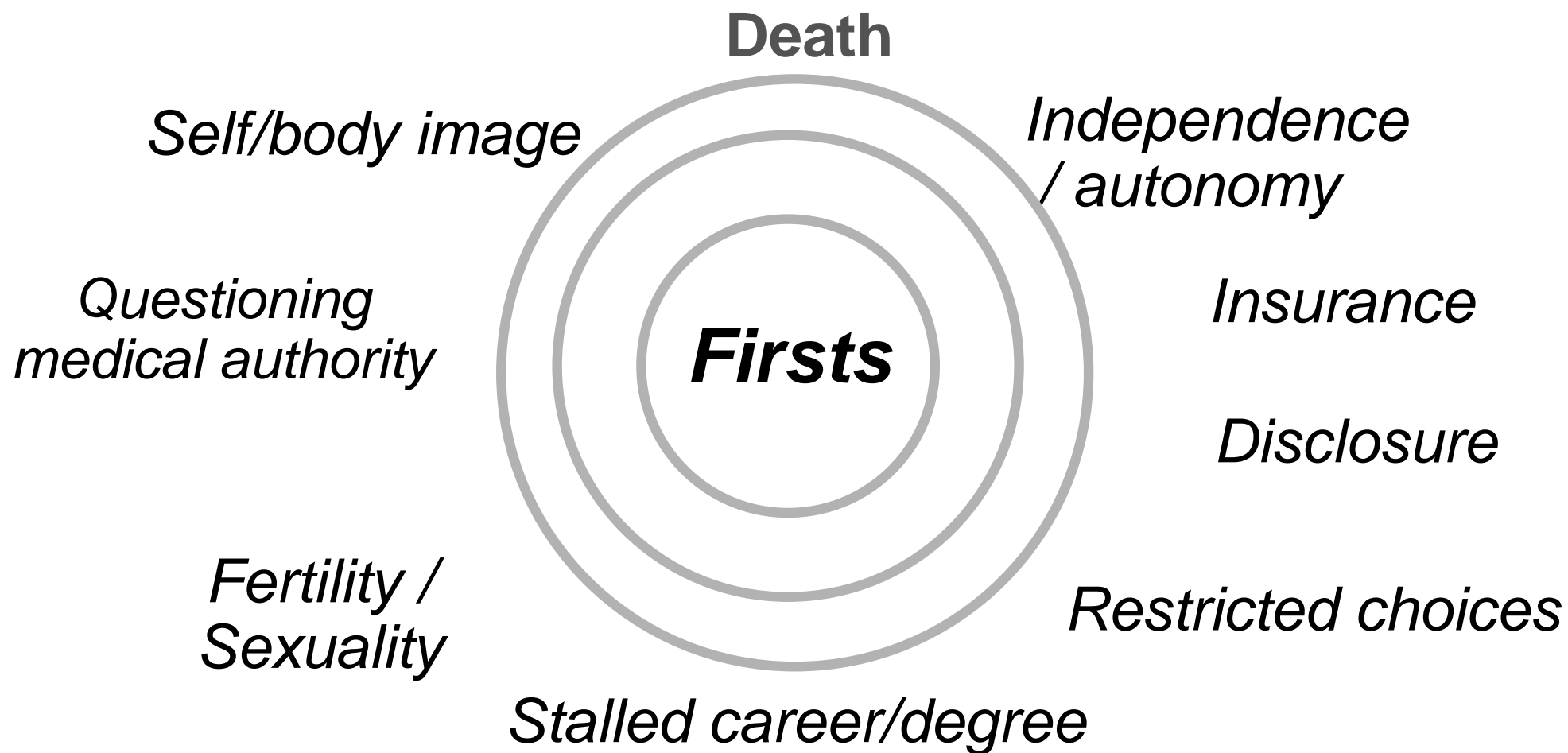
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Issues - Steep learning curve



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Dropped off a cliff

- Many don't even begin to process their cancer experience until later. Sometimes much later.
- Cancer history sets them apart from peers.
- Many more years of dealing with repercussions.
- Critical to enlist them as partners while in treatment in order to turn over responsibility of follow-up.

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KIDS



**Pediatric Hospital*
**Pediatric oncologists*
**9 out of 10 patients seen*
< age 15



**NO
MAN'S
LAND**



*70,000
cancer
patients
per year*

OLD PEOPLE



**Adult Hospital*
**Medical Oncologists*
**9 out of 10 patients seen*
> age 40

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Issues - Lack of Relevant Resources

Twofold problem:

- LACK of relevant resources.
- Lack of RELEVANT resources.

What's The Secret?!?

(or, how the #\$%^ do you talk to these patients and survivors?)

1) Not Easy

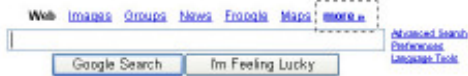
2) To reach your target audience most effectively, go to

WHERE THEY ARE

and speak to them in a way that will

RESONATE WITH THEM.

And now, we interrupt this presentation for a brief tour of modern young adulthood...



[Advertising Programs](#) - [Business Solutions](#) - [About Google](#) - [Get the Google Canada](#)

[Make Google Your Homepage!](#)



Scary...



**photo courtesy of SS+K, Young Adults: Marketing Trends (Nov. 2006)*

Scarier...



**photo courtesy of SS+K, Young Adults: Marketing Trends (Nov. 2006)*

Scariest!

flickr™



MySpace - Microsoft Internet Explorer

Address: http://myspace.com/

myspace.com. a place for friends

Home | Browse | Search | Invite | Film | Mail | Blog | Favorites | Forum | Groups | Events | Videos | Music | Comedy | Classifieds

Books NEW! | Chat Rooms | Games | Music Videos | Blogs | Comedy NEW! | Horoscopes | MySpaceIM NEW! | Careers | Filmmakers | Movies NEW! | Schools

myspace music videos

watch: Go To Church (Ft. Snoop Dogg & Lil Jon)

Member Login

E-Mail:

Password:

Remember Me

Forgot your password?

Cool New People

rich | Juan | Faisal

Videos presented by: Xingular

MySpace Music [more music]

The Shys
Rock / Soul
Los Angeles, CA

The Shys' debut record "Astoria" hits stores next week, but it sounds like it could've been out for ages. Channeling the Stones, Bowie and T-Rex, their music recalls the rock 'n' roll swagger of decades past yet remains fresh and lively.

» Listen Now

Safari | Facebook (29) | Brock Yetso

http://www.facebook.com/brockyetso

facebook

Brock Yetso

Wall | Info | Photos | Boxes | Video

What's on your mind?

Ulman Cancer Fund for Young Adults Brock Yetso comments on ways to give during the holiday season! Give with us...

Ulman Cancer Fund for Young Adults It is better to give than it is to get | Ulman Cancer Fund for Young Adults' Blog

Ulman Cancer Fund for Young Adults Last December, I learned the truth to this saying more than ever. I was visiting with patients at the University of Maryland Eastern Shore Cancer Center when I met a 21 year old woman that had a profound impact on me and changed the way the Ulman Cancer Fund for Young Adults celebrates the holiday sea

Brock Yetso was tagged in Ulman Cancer Fund for Young Adults' album.

Volunteer and Sponsor Appreciation Event
December 1 at 3:42pm

Safari | Ulman Cancer Fund (ulmancancerfund) on Twitter

http://twitter.com/#/ulmancancerfund

Ulman Cancer Fund (ulmancancerfund)

Ulman Cancer Fund @UlmanCancerFund

Supporting, educating, connecting and empowering young adults and their loved ones affected by cancer. Tweets by @sarahbrockhol

http://www.ulmancancerfund.org

Timeline

UlmanCancerFund Ulman Cancer Fund
JUST ANNOUNCED: prize for best outfit at YACS B'more Holiday Party and Gift Drive. Think it will be you?
2 hours ago

UlmanCancerFund Ulman Cancer Fund
Holiday playlist is nearly finalized for YACS B'more Holiday Party and Gift Drive. Does anyone have good...
3 hours ago

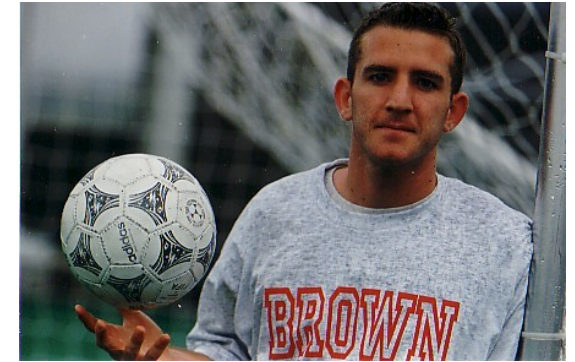
UlmanCancerFund Ulman Cancer Fund
It's not too late to get this shorty union suit for the YACS B'more Holiday Party and Gift Drive. Remember, it...
4 hours ago

UlmanCancerFund Ulman Cancer Fund
Brock Yetso comments on ways to give during the holiday season! Give with us...
5 hours ago

UlmanCancerFund Ulman Cancer Fund
The UCF blog home page hit 1,000 unique views today. Haven't seen it yet? Check it out...
5 hours ago

THE ULMAN CANCER FUND FOR YOUNG ADULTS

- Founded in 1997 by Doug Ulman & his family to fill a void that exists in health care services. Doug was diagnosed with cancer in college at age 19 as a sophomore at Brown University.
- Over a decade of service
- 3-time cancer survivor & received treatment in Maryland
- President & CEO of the Lance Armstrong Foundation and former Chair of NCI Consumer Liaison Group
- Diana Ulman – Gov Council on Cancer Control



“At a time when I was supposed to be discovering my independence, I was suddenly pulled back to my family and I was incredibly dependent on those around me”

-Doug Ulman

MISSION

The Ulman Cancer Fund for Young Adults enhances lives by supporting, educating and connecting young adults, and their loved ones, affected by cancer.

UNIQUE CANCER BURDEN

Psychosocial

- Interruption of normal developmental trajectory
- Isolation (peers and other patients)
- Decision making
- Forming of intimate relationships; fertility preservation and family planning

Medical

- Lack of progress (5 year survival rate), compared to other age groups
- Risk and poor outcomes under-recognized
- Approx 60-70,000 new cases annually (6% of all new cancer diagnoses)
- Leading disease cause of death for women and second for men

AVERAGE ANNUAL % CHANGE IN YA SURVIVAL RATES

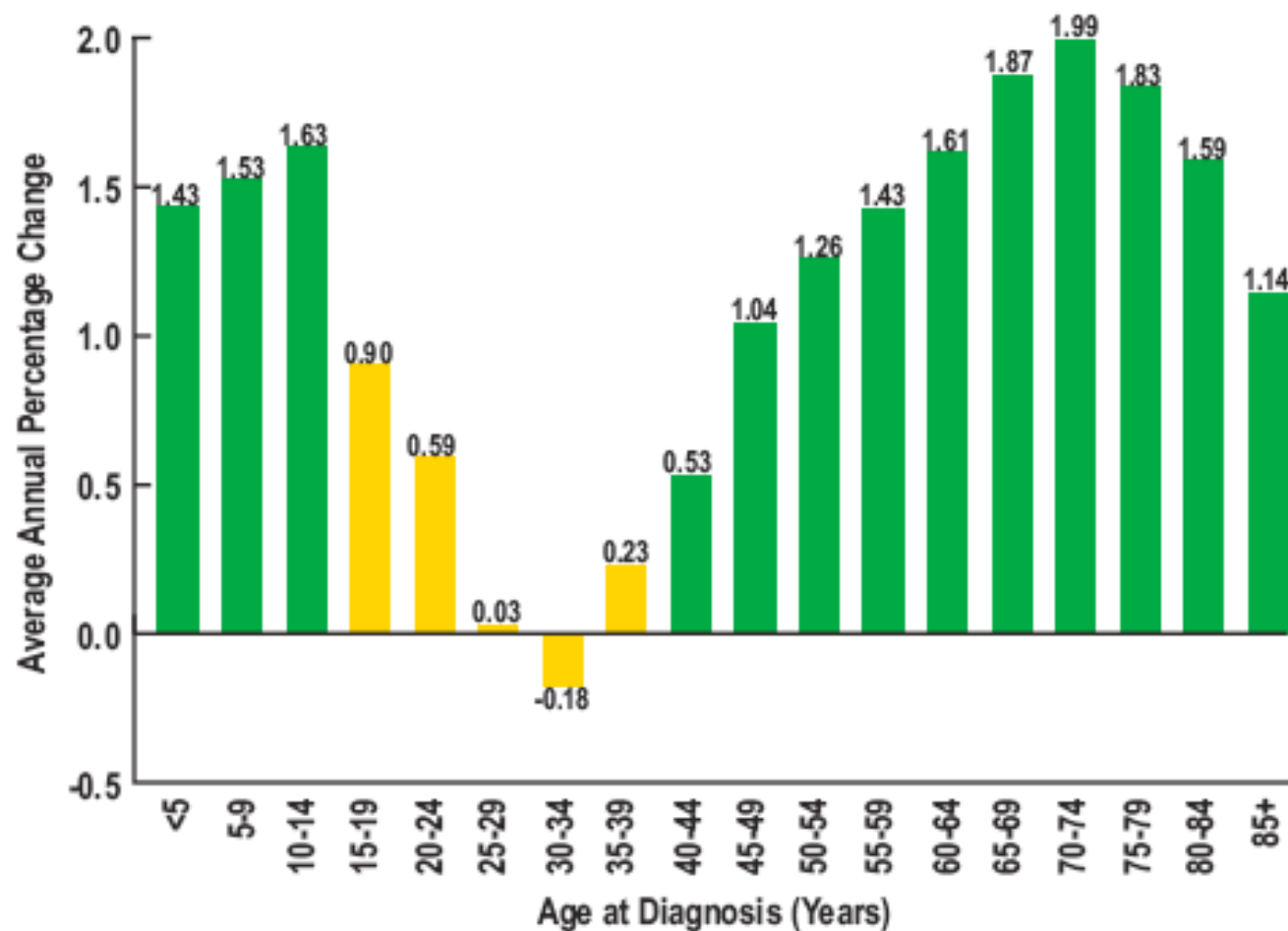
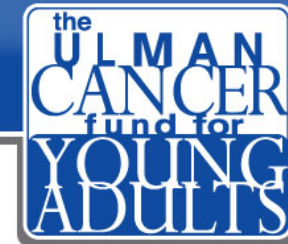


Figure 2. Improvement in 5-Year Relative Survival, Invasive Cancer, SEER 1975-1997
SEER Monograph 2006

How we're addressing these challenges

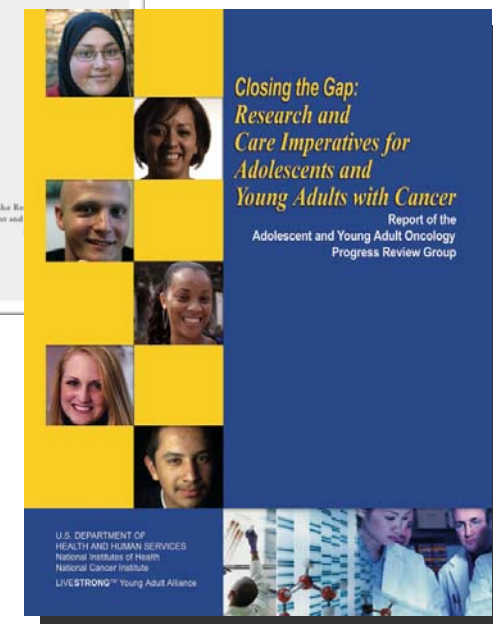
- Go where young adults are
 - Patient Navigation
- Create unique and varied opportunities to communicate with target audience
 - New Media
 - Social Communities
 - Sport
- Collaboration & Innovation
 - LIVESTRONG Young Adult Alliance

Going where they are....



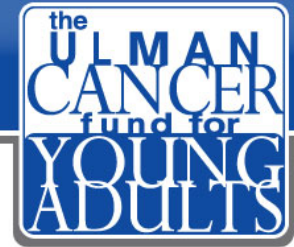
UCF Navigation Program Background & Timeline

- UCF is leading young adult cancer support organization in country since 1997
- Providing patient navigation services remotely via toll-free hotline, website and email since 1997
- Need Identified: Adolescent & Young Adult (AYA) Patient Navigation & Underserved Populations
 - National Cancer Institute AYA Progress Review Group Report I 2006
 - LIVESTRONG Young Adult Alliance PRG Implementation Report in 2007
- 2007 - \$100K commitment to UCF by Lance Armstrong – develop model program
- 2008 – LIVESTRONG/Nova Research Environmental Scan of existing programs in United States
- February 2008 – University of Maryland (UMGCC) partnership/program begins
- May 2010 – UMGCC Program evaluation (LIVESTRONG) and funding diversification (UMGCC & other partners)

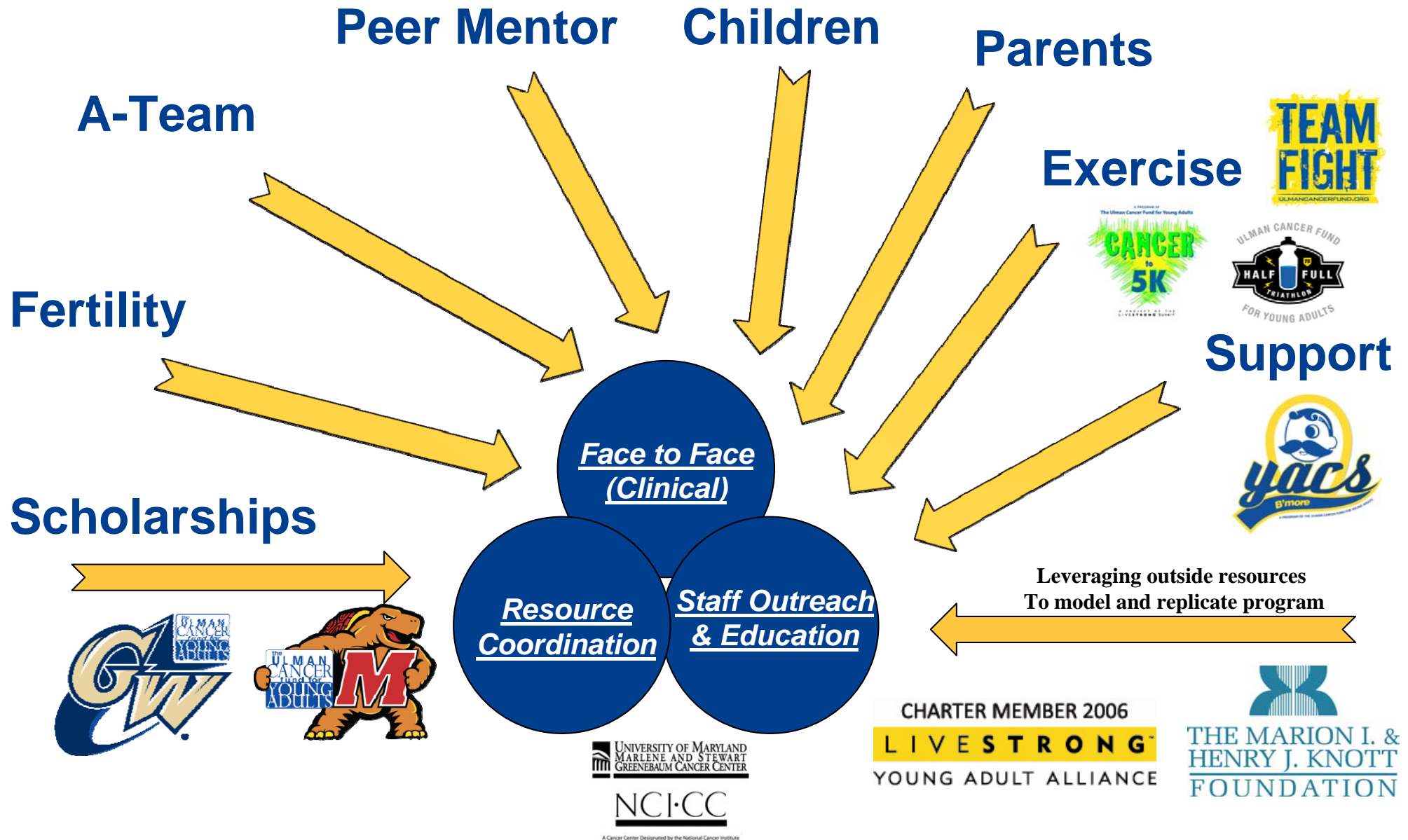


Elizabeth Saylor, MSW
– Director, UCF Patient Navigation Program

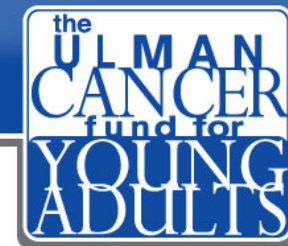
UCF Patient Navigation



A closer look...what is UCF Patient Navigation



UCF Patient Navigation



UMGCC Program Achievements

- 212 patients seen in 2010
- Access to medical records
- Designated webpage on UMGCC website
- Chemotherapy consent and fertility protocol
- Visits to Program/Cancer Center by several high profile individuals
- Univ. of MD designated College Scholarship
- The ONLY Young Adult Patient Navigation Program in country at NCI Designated Cancer Center
- Expanding model to other cancer centers

The screenshot shows the UMGCC website with sections for 'Information for Patients', 'Information for Patients Young Adult Patient Navigator', 'Related Resources', and 'For More Information'. It includes a list of services like 'Patient Care', 'Being a Survivor', and 'UMGCC Directory'. There are also social media icons for Twitter, Facebook, and YouTube, and a 'Share this page' section.



Todd Heap

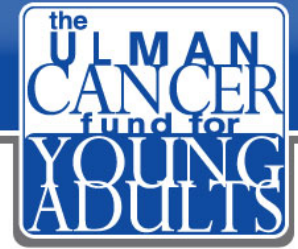


Todd Rauch & Vern Yip



Univ. MD College Scholarship

Unique & Varied Opportunities...



New Media

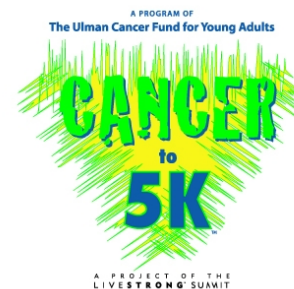
- Videos
- Blog – daily
- Twitter & Facebook

Social Communities

- YACS (Young Adult Cancer Support) Baltimore & DC

Sport

- Cancer to 5K
- Half Full Triathlon



L I V E S T R O N G™

YOUNG ADULT ALLIANCE

- Inaugural meeting November 2006
- Formed to implement PRG recommendations
- Mission: Improve survival rates, quality of life and quality of care for young adults facing cancer.
 - Approx. 156 organizations (advocacy, medical institutions, government)
 - Work organized in 4 main areas
 - Standards
 - Science
 - Awareness
 - Membership

Member Resources

LIVESTRONG™ YOUNG ADULT ALLIANCE

- Ulman Cancer Fund for YAs
- Fertile Hope
- Young Survival Coalition
- Young Cancer Spouses
- Pregnant With Cancer
- Cancer and Careers
- RealTime Cancer
- First Descents
- Rise Above It
- The Colon Club
- Imerman Angels
- FORCE
- Tamika & Friends

- *TigerLily Foundation*
- *Yellow Umbrella*
- *CanTeen*
- *Prepare to Live*
- *Sharsheret*
- *mAssKickers*
- *I'm Too Young for This*
- *MyLifeline*
- *Testicular Cancer Resource Center*
- ***AND MORE...!***

251 individuals representing approx 156 organizations

91 Advocate Organizations

65 Provider/Medical Organizations

2 Government Liaison Organizations

Closing Thoughts...

*HOW you and WHERE you are offering support
is just as important as
WHAT you are offering for support*

THANK YOU!