



Young Adults & Cancer A Growing Need

Maryland State Council on Cancer
Control Conference

November 15, 2004

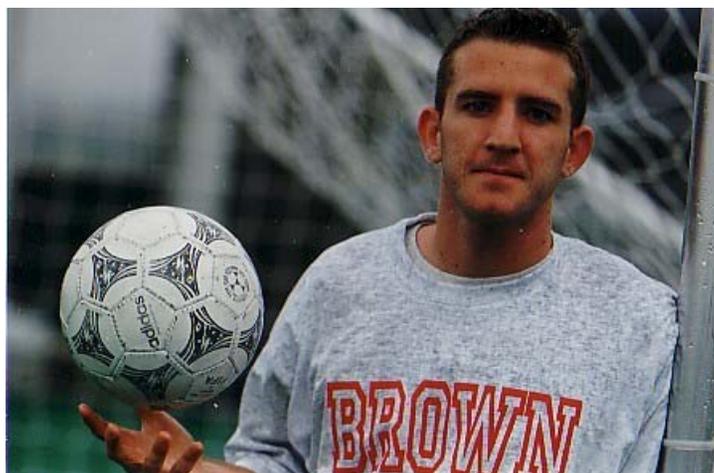
By: Brock Yetso



OBJECTIVES

- Background – Ulman Cancer Fund
- Young Adult Population
- Survivorship Programs

DOUG ULMAN – Personal Story



- College student-athlete at Brown University
- Diagnosed with cancer at age 19

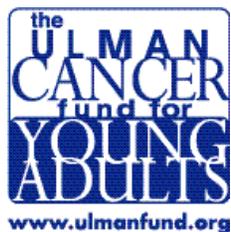
“At a time when I was supposed to be discovering my independence, I was suddenly pulled back to my family and I was incredibly dependent on those around me”

-Doug Ulman



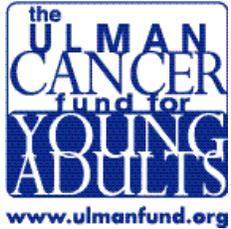
DOUG ULMAN – Personal Story

- Young people don't get cancer
- Few to no resources/organizations for young adults with cancer



VOID/LACK OF SERVICES

- ✓ NO organizations/resources available for young adults affected by cancer
- ✓ Young people DO get cancer

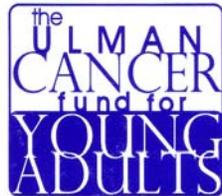


UCF – Created to fill a void

bookmark us

@

www.ulmanfund.org



Supporting young adults
affected by cancer

learn about our:

- support groups
- survivors' network
- guide to survival
- scholarship fund
- cancer awareness and prevention
- support services

or contact us @

the ULMAN
CANCER
fund for
YOUNG ADULTS

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The Ulman Cancer Fund for Young Adults provides support programs, education and resources, free of charge, to benefit young adults, their families and friends, who are affected by cancer, and promotes awareness and prevention of cancer.

- Founded in 1997 to fill a void that exists in health care services

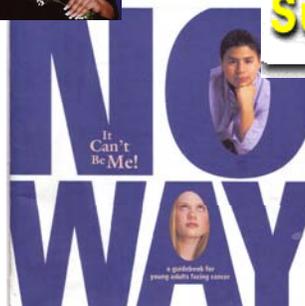
- First non-profit group in the country solely focused on the young adult population

MISSION

To provide support programs, education and resources, free of charge, to benefit young adults, their families and friends, who are affected by cancer, and promotes awareness and prevention of cancer.

UCF – Created to fill a void

- The Survival Guide
- Support/Networking Group
- Survivors/Loved Ones Network
- Patient Advocate Program
- College Scholarships
- Speaker's Bureau
- Patient Navigator Program



Survivor's Network

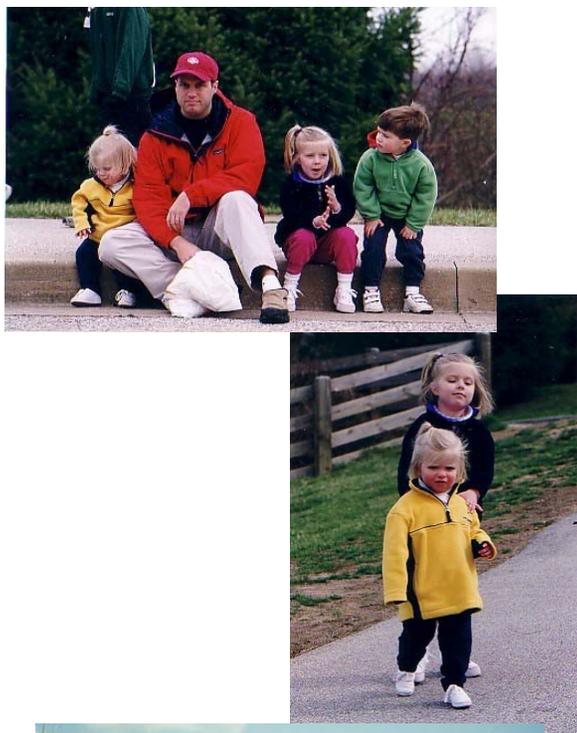


Scholarship Info.



Young Adults & Cancer DEFINITIONS

Who is a CANCER SURVIVOR?



- Anyone who has been diagnosed with cancer from the time of diagnosis to the end of life.

- Caregivers & family members are also cancer survivors.

Young Adults & Cancer DEFINITIONS

Who is a Young Adult (YA)?

- Ages 18 – 35

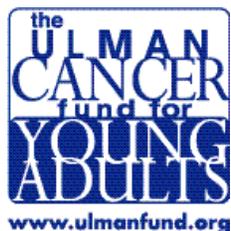
Issues related to cancer survivorship for this population

- Fertility
- Dependence/Independence
- Insurance
- Dating/Relationship
- College
- Employment....



Challenges that Face 15-35 Year-Olds





In young adults, cancer is #1 disease killer

Top 5 Causes of Death due to Disease* Age 20-39, U.S., 2000

Males and Females

1	Cancer 10,449
2	Suicide 10,277
3	Heart Disease 7,919
4	HIV Disease 5,477
5	Cerebrovasc. Disease 1,614

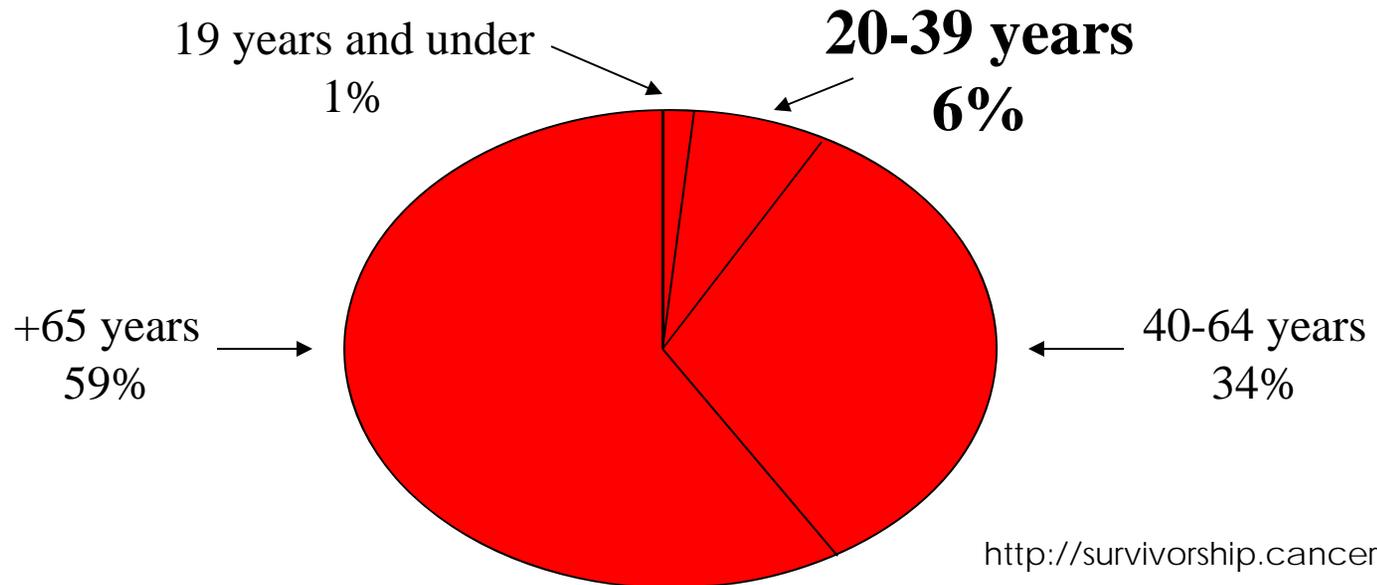
*Accidents and Homicide excluded; Modified from Ca-A Ca J for Clin 53:5-26, 2003

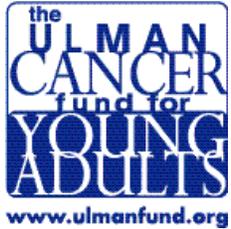
Young Adults & Cancer

It is currently estimated that there are **9.8 million cancer survivors** in the United States, representing approx. 3.5 % of the population.

Growing Need

Estimated # of persons alive in the U.S. diagnosed with cancer in the last 20 years by current age





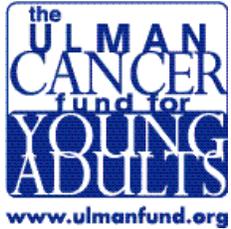
Young Adults & Cancer

Cancer Diagnosis

- Treatment decisions
- Psychosocial issues
- Recurrence ?
- Late effects of cancer treatment
- Long-term follow up
- Cancer Survivorship?

Cancer Diagnosis & Young Adults

- Changing jobs
- **Uninsured/Underinsured**
- Finding people that truly understand
- Fertility options
- Dating
- School...



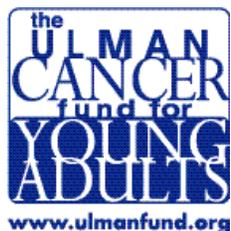
Young Adults & Cancer Uninsured/Underinsured

People **18-24 years of age** are the largest population of uninsured people in our country

Nearly 50%

People **25-34 years of age** are the 2nd largest population of uninsured people in our country

Over 30%



Young Adults & Cancer Uninsured/Underinsured

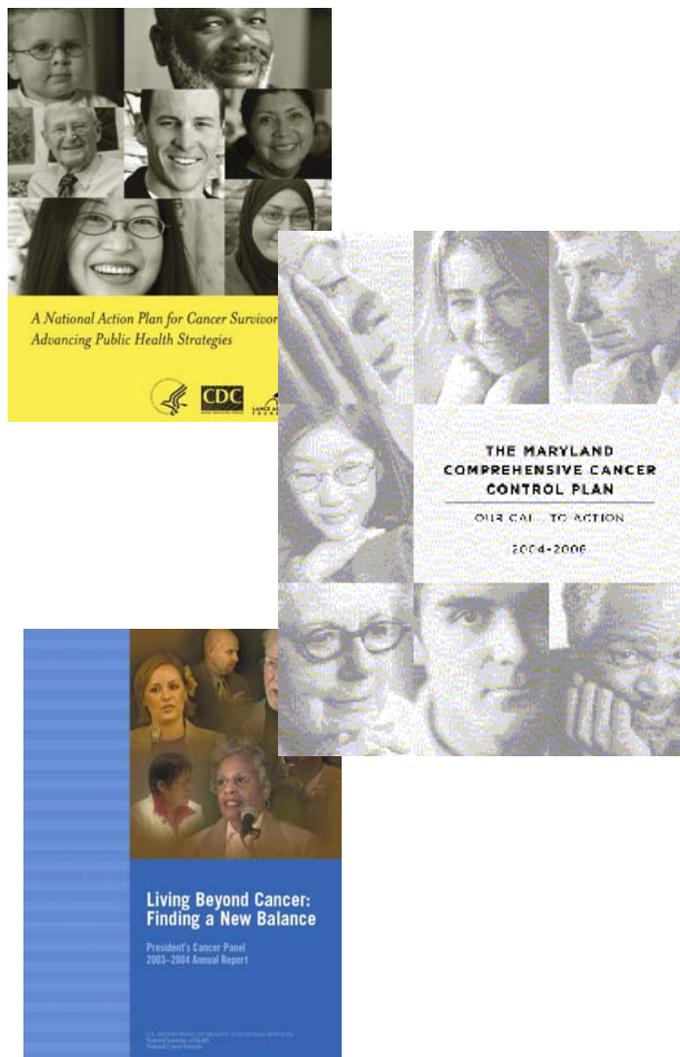
August 27, 2004

Record Level of Americans Not Insured on
Health

New York Times

*More than **10 million** of those **without insurance** were young people, **25 to 34 years old**, government officials said, an increase of 576,000 from 2002. "Young adults got hammered," said John F. Holahan, a health economist at the Urban Institute, a nonprofit research center in Washington.*

Young Adults & Cancer Areas of need

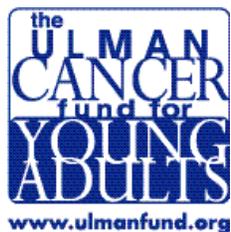


Problems:

- "Access to information and resources"

Strategies:

- "Identify & develop Patient Navigator tools/programs"
- "Develop & implement multimedia public service campaign to empower public to be informed ...proactive consumers"



Young Adults & Cancer Patient Navigator Program

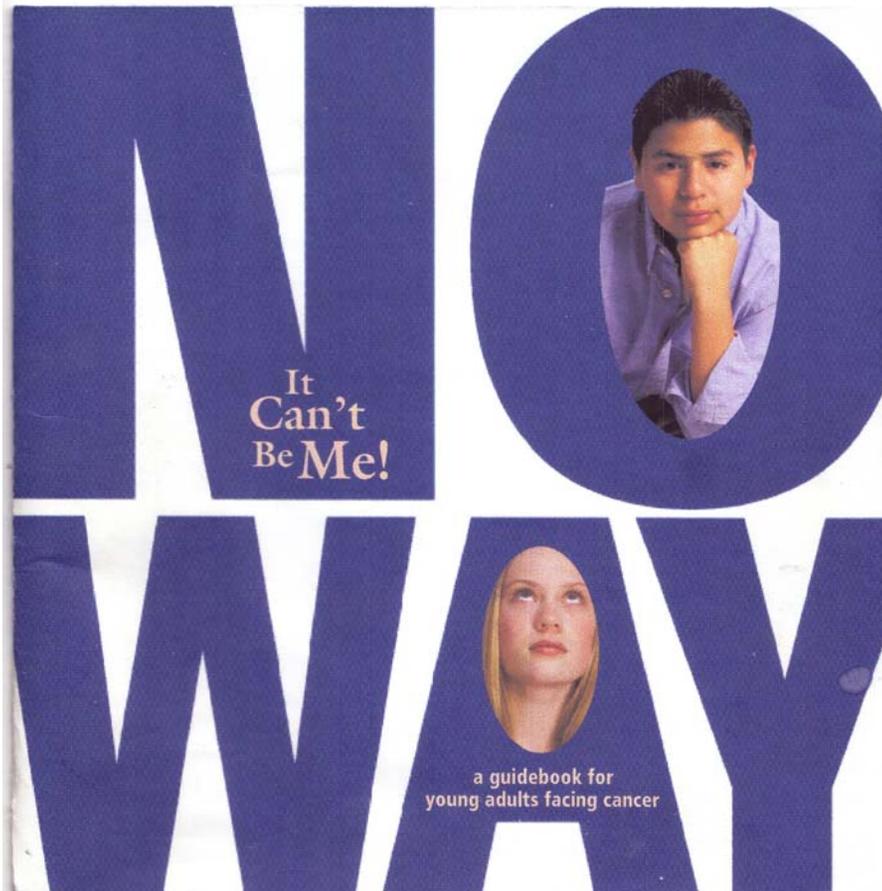
2 Year Grant – LAF
Johns Hopkins University
Sidney Kimmel Cancer Center

GOALS:

- Friendly Voice
- Create Advocates – help patients become more proactive in their Survivorship
- Provide access to information & resources

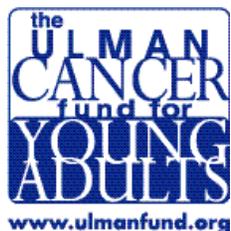


Young Adults & Cancer Guide To Survival



Chapters entitled:

- 1) *Start With An Education*
- 2) *The Folks in White Coats*
- 3) *Some Record Keeping*
- 4) *Reactions & Actions*
- 5) *The People & Issues In My Life*
- 6) *A Parent's Perspective*
- 7) *On To Hope*



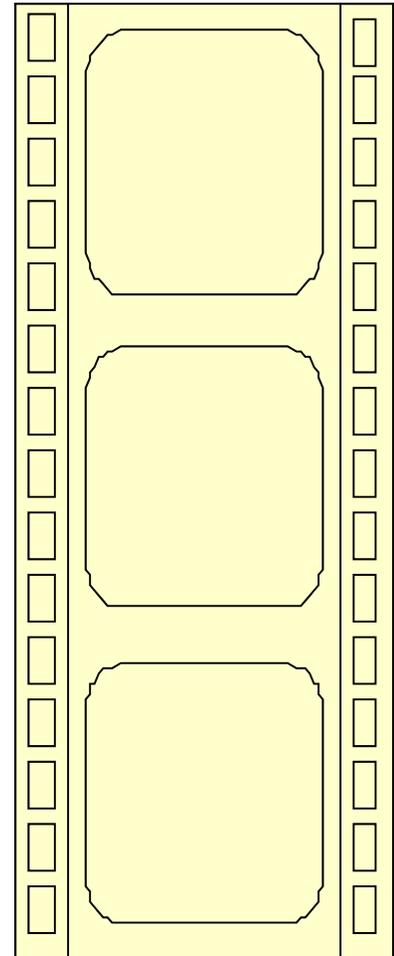
Young Adults & Cancer Guide To Survival

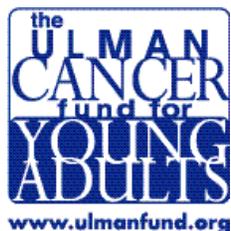
- Publication & Distribution – 5,000 copies
- Evaluation – online survey, tear out postcard survey, follow-up survey/interviews with Medical Professionals



Survivorship Documentary Film

Eden Stotsky – colon cancer survivor





The Changing Demography of Cancer Survivorship

- 64% of adults diagnosed with cancer today will be alive five years from now
- Among children, the 10 year survival rate is approaching 75%.
- Over 80% of all cancer patients are treated in the community
- Cancer for many has become a chronic illness
- Cancer is for most, a family illness



What this all mean

Collaboration, Partnerships, Teamwork...

"There is no limit to what can be accomplished if it doesn't matter who gets credit."

-Ralph Waldo Emerson