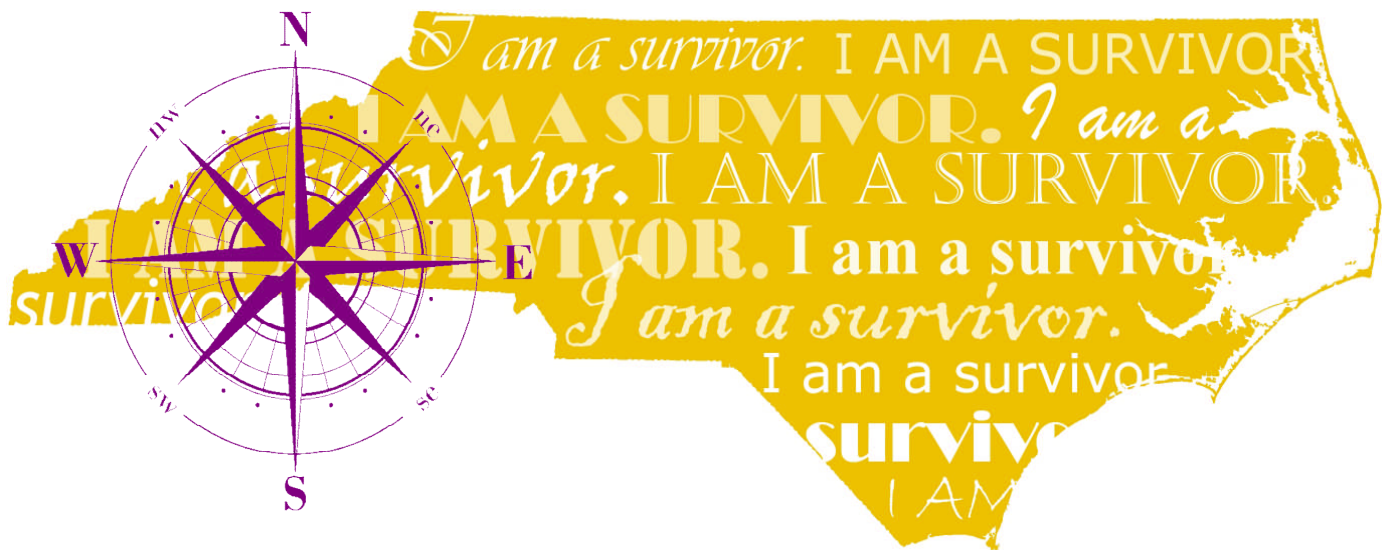


North Carolina Comprehensive Cancer Program (NCCCP)
Survivorship Summit
June 25 – 26, 2009 • Greenville, NC



Charting the Course for Survivorship

3rd Annual North Carolina Cancer Survivorship Summit
Charting the Course for Survivorship
June 25th -26th, 2009
Hilton Hotel – Greenville, NC

Cancer survivorship begins at the time of diagnosis and continues the balance of life and makes up the cancer continuum.

Continuing the conversation of cancer survivorship in NC, a 3rd Annual North Carolina Cancer Survivorship Summit has been held. The North Carolina Comprehensive Cancer Program (NCCCP) has traveled across the state (Durham - RTP, Winston-Salem, and Greenville), listening to the voices of "Survivors", those who need facilitation and support.

Vision

Provide a summit in which cancer survivors are offered opportunity to increase their knowledge and awareness of cancer and cancer resources in North Carolina, and a forum to allow survivors to speak out regarding education, prevention, screening, diagnostic and treatment services in order to facilitate a continuum of care that is quality centered for the patient and family and that embraces and provides for meeting the needs of all those touched by cancer.

Objectives: To assist all cancer survivors, patients, families, caregivers and those touched by the burden of cancer in the following areas:

- Empowerment to understand and manage their personal needs (physical and psychosocial) as related to cancer treatment, to activities of daily life and to overall health, well-being and survival
- Facilitate caregivers abilities to care for and advocate for the cancer patient as well as themselves by providing information, resources, and support
- Provide information regarding resources in order to reduce the fiscal (insurance, legal, employment) barriers and other related financial hardship issues related to optimal care and support for cancer patients and their loved ones
- Reduce geographic barriers to optimal care and support for cancer patients and their loved ones
- Provide healthcare professionals opportunities to engage in continuing education, training workshops, and other educational venues in order to develop knowledge and communication skills to meet the needs of multicultural and multiethnic patients, their loved ones, and/or caregivers
- Provide a forum for Adolescent and Young Adult survivors to address survivorship issues specifically related to their population

This event was made possible through the support of our partners across the state:

University Health Systems, Pitt County Memorial Hospital

American Cancer Society

UNC Lineberger Comprehensive Cancer Center – N.C. Cancer Hospital

Carolina Well – UNC Lineberger Cancer Survivorship Program

Duke University Hospital - Duke Center for Cancer Survivorship

Duke Comprehensive Cancer Center

Wake Forest University Baptist Comprehensive Cancer Center

Cancer Centers of North Carolina

Leukemia and Lymphoma Society

PPD

Certicode – The Cancer Registry Specialists

Daniels Tours

Maola

Location and Logistics

Held June 25th – 26th, 2009, the 3rd Annual Cancer Survivorship Summit was in Greenville, NC at the Hilton Hotel. Many partners from across the state worked with the CCCCCP to provide a 2 day celebration for survivors, caregivers, advocates and health professionals. There was no cost to attend. The partnership with University Health Systems – Pitt County Memorial Hospital and others enabled the NCCCCP to recruit 300 survivors, caregivers, advocates and health professionals. This is the highest number of summit participants attending to date. Summit attendance has grown annually. Proudly, North Carolina Governor Beverly E. Perdue proclaimed June as Cancer Survivorship Month in North Carolina. Greenville's Mayor Patricia (Pat) Dunn opened the conference with a welcome to all, and introduced the City of Greenville's proclamation, that June 25-26, 2009, be earmarked as Cancer Survivorship Commemoration Days.

In an effort to defray costs to survivors, lodging scholarships were provided to 55 cancer survivor participants (1 or 2 night hotel accommodation based on travel distance to summit) at the rate of \$109.00 per night. These survivors would not have been able to attend the summit had they not been awarded the scholarship. Scholarship accommodations were made possible by NC Comprehensive Cancer Program, American Cancer Society, Duke Comprehensive Cancer Center, Wake Forest University Baptist Comprehensive Cancer Center, Cancer Centers of North Carolina, and University Health Systems, Pitt County Memorial Hospital. In addition, Daniel Tours provided free transportation to the summit for survivors living in the Wilmington area.

A planning committee was formed to map out the summit. The committee met bi-weekly via conference call and face to face as needed. The objectives for the summit were extracted from the Survivorship section of the NC Cancer Plan (www.nccancer.com). These objectives were developed by the NC Cancer Partnership Survivorship Work Group. The planning committee developed the agenda based on the objectives that were identified and requests from participants of former years.

Efforts were made to utilize local resources when identifying presenters (professional and entertainment). Special consideration was made to ensure that the entertainment and healthy activities provided enhanced survivorship awareness and increased self-efficacy. Workshops (Welcome Back: Facilitating the School Experience for Childhood Cancer Survivors, How to Begin a Support Group in Your Area, Physician/Patient Communication, and Advocacy 101) were added to this year's summit, per suggestions given at last year's summit. The workshops were action oriented, once the participant completed the workshop they had the tools needed to implement the activity in their perspective communities. Evaluation and verbal feedback indicates that those attending the 2009 Survivorship Summit went away feeling inspired and empowered to make a difference in their communities in cancer survivorship.

Summit Planning Committee

Sharon Bigelow, NavigateCancer Foundation

Paula Bowen, Pitt County Memorial Hospital

Suzanne Carroll, Wake Forest University Medical Baptist Center

Holly D'Addurno, Duke Center for Cancer Survivorship

Phyllis DeAntonio, Pitt County Memorial Hospital

Collen Fenlon-Code, Pitt County Memorial Hospital

Mindy Gellin, UNC Lineberger Cancer Survivorship Program

Kim Jasek, Cancer Centers of NC

Laura Kujawski, NCI's Southeast Region Cancer Information Service

Michelle Manning, UNC Lineberger Cancer Survivorship Program

Loreal Massiah, Leukemia and Lymphoma Society

Susan Melchoin, Cancer Centers of NC

Pam Schmid, Priorities Simplified

Tina Shaban, Duke Center for Cancer Survivorship

Cornell Wright, Center for Health and Healing

Kenisha Bethea, NC Comprehensive Cancer Program

Dianah Bradshaw, NC Comprehensive Cancer Program

Tawanda Burno, NC Comprehensive Cancer Program

Molly Black, NC Comprehensive Cancer Program/American Cancer Society

Clifton Langley, NC Comprehensive Cancer Program/American Cancer Society

Rachel Urban, NC Comprehensive Cancer Program/American Cancer Society

Rachel Walton, NC Comprehensive Cancer Program/American Cancer Society

Cancer treatment centers, hospitals, not for profit organizations, cancer support programs, advocacy groups, pain management and palliative care, hospice and end-of-life, smoking cessation, and physical activity and nutrition exhibitors were available to answer questions and provide information and/or resources as needed. The 36 exhibitors are listed below.

- Hope Mobile
- Duke Medical Center
- The Duke Center for Cancer Survivorship
- Lineberger Cancer Center, Survivorship Program, University of North Carolina, Chapel Hill
- Wake Forest University Comprehensive Cancer Program
- Pardee Hospital
- Pitt County Memorial Hospital
- American Cancer Society
- Cancer Services, Inc.
- CaringBridge
- Carolina Community Network
- Cancer Information Service (CIS)
- Center for Health and Healing
- Cornucopia House Cancer Support Center
- Wind River Spiritual Center
- Colon Cancer Alliance
- Leukemia Lymphoma Society
- North Carolina Lung Cancer Partnership
- Prostate Cancer Coalition of North Carolina
- Susan G. Komen for the Cure
- I'm Too Young for This! Cancer Foundation
- Make-A-Wish Foundation of Eastern North Carolina
- Avila Physical Therapy
- Priorities Simplified, LLC
- NavigateCancer Foundation
- Patient Advocate Foundation
- Palliative Care Unit, Wake Forest University Medical Center
- Carolinas Center for Hospice and End of Life
- Community Home Care and Hospice
- Tobacco Prevention, North Carolina Tobacco Use Quitline
- Environmental Polymorphism Registry

Break-out Sessions were provided to assist and facilitate survivors and others touched by the burden of cancer, and to introduce new methods of dealing with the multiple problems and consequences arising from a cancer diagnosis. Information sessions, provided by content professionals were available as follows:

- Caring for the Caregiver
- Adolescent and Young Adult Cancer / I'm Too Young for This
- Cognitive Functions (Chemo Brain)
- Sexuality and Intimacy / Self Esteem (Body Image)
- Prostate Cancer in NC
- Navigating Mountains of Financial Bills and Woes
- Pain and Palliative Care
- Getting the Most Benefit from Your Doctor's Visit: Questions to Ask
- Psychosocial Issues
- Physical Activity and Nutrition
- Patient Navigation

Workshops to teach new information for dealing with cancer as a diagnosis or with other identified priorities were provided in the following areas

- Welcome Back: Facilitating the School Experience for Childhood Cancer Survivors
- How to Begin a Support Group in Your Area
- Physician/Patient Communication, Utilizing and Electronic Patient Medical Record
- Advocacy 101

Survivor summit participants are always ready to come together to network and to share in joyous activities celebrating surviving cancer. Entertainment sessions for the 2009 Summit included these:

- A preconference gathering, with refreshments, was provided the night before the official opening of the Summit. Icebreakers and activities to get participants who were staying overnight into the spirit of sharing and networking was the goal.
- Another session "Voices of Light" is a story of Hope, Humor, Gratitude, Joy, Service, and Never-Ending Faith. It was provided by the Breast Cancer Support Group of the Burke County Cancer Survivors of Blue Ridge Healthcare. This group is located in Burke County, NC
- Roger and Kathy Cawthon's "*The Cancer Crusade*". Roger and Kathy Cawthon, both 13-year survivors, presented their nationally known signature program entitled, Medicine, Marathons, and Miracles. www.thecancer crusade.com
- Marcy Brennar, Dead Girl Walking was presented by North Carolina native Marcy Brenner, who was diagnosed at 34 with breast cancer, the same year she lost her mother to ovarian cancer. This presentation, Marcy's story, takes her from the brink of despair to being truly alive again. www.deadgirlwalking.net
- Barbara Bates Smith, The C-Word: A Life-meets-Art Cancer Story. This is the frank, humorous, and poignant story of the presenter's role in the play "*Wit*" and of her own breast cancer. www.thecancer crusade.com
- Eugene Taylor presented "Djembe Talk", a narrative presentation of story telling with a djembe drum, native to South African tribes. Geoready2go@aol.com

The Healthy Activities presented during the 2009 Survivorship Summit left participants ready to make changes in their nutritional intake, ready to look and feel better and ready to share their stories to inspire others facing cancer's burden. Activities presented included:

- Look Good . . . Feel Better Booth (interactive) – American Cancer Society
- Cancer and Nutrition (food taste testing/sampling) – American Dietetic Association and Oncology Dietician
- Faces of Cancer (share your face and story) – North Carolina Comprehensive Cancer Program
- Signing the Cawthon's Hopemobile

Three hundred participants, representing 52 counties and numerous types of cancer, identified and shared successes, barriers/challenges, action steps, stories, tears and hugs.

The following is a synopsis of breakout sessions and feedback from participants.

Getting the Most Benefit from Your Doctor's Visit: Questions to Ask

Group Questions

- How can I ask physician for pain meds and not hurt his ego?
- How do I achieve systematic coordination of care?
- What questions are appropriate/best/good to ask from those meeting with variety of cancer patients?
- Can I get test results over the phone if I'm OK when I have good insurance and don't want to waste time?
- How can I advocate for myself when physicians don't want to see me until a month away?
- Why do we have to request our reports to learn diagnoses that they never tell?
- Is someone involved with cancer background in Washington, DC?
- New treatments and developments...how do I inform my doctor?
- How do you assist patients with questions to ask doctor for treatment services

What Works

- Keep copies of reports (pathology, scans, all parts of records, radiation summary) store on flash drive and/or disk so that you will both a hard and soft copy
- Bring a self advocate
- Make friends with RN's and NP's (take with you to appointments and have them take notes
- Keep pharmacists involved and ask them questions
- Have a list of questions prepared
- Ask for 2nd opinion outside network
- Ask insurance company, don't rely on just the doctor office information provided
- Communicate with doctor
- Get test results during oncologist appointment

Overall Need

- Improved quality of Care and Coordination

Sexuality and Intimacy

- Issues should be brought to the MD attention early for better long term benefits
- Support groups – do they create barriers with friends and family? Concerns and anxieties shared with support group, exclude family out of survivor’s experiences
- Support groups create open environments and offers advice/solutions to help open up to family and friends and identify people to approach
- Family members feel survivor needs to hear other people’s experiences to assist with coping
- Sexuality is sometimes avoided in certain support groups – need someone to initiate the topic
- Increase information obtained through events and support groups, open up avenues of communication and the ability to open up to individuals in need of emotional support
- Visit focus groups in different areas, try out various groups to find a good fit
- Addressing issues pre-treatment will help post-treatment
- Concerns of losing spouse and/or partner due to intimacy issues
- Use correct terminology of body parts – vagina/penis
- Comfort level of asking the questions

Programs that are available around sexuality/intimacy – MD Anderson has a great program that may be used as a resource.

Prostate Cancer Recovery Enhancement for African American Men and their Intimate Partners (PROCARE) – teleconference program, family friends, anyone

Nutrition

- Benefits of red vs. green vegetables and fruits; is it better to stick with one over the other one
- What are the benefits of the new fruit extracts and juice bars?
- Pros and cons of grilling food
- What is different about the nutrition needs of patient with mets vs. newly diagnosed?
- What is the latest about hormones in our food
- Discussed eating correct proportions and physical activity
- Splenda vs. sugar; does sugar feed cancer?
- What about new herbal teas, green tea, black tea

Adolescent and Young Adult

Intended Outcomes/Goals for AYA needs:

- Educate the health care system (especially doctors)
- Educate Young Adults- especially on the topic of “survivorship”
- Continuing to have visibility through media outlets like: facebook, twitter, blogs
- Educating local businesses, community colleges, high school systems (Kiwanis Clubs), local churches, school nurses, local health departments on AYA needs, barriers and resources for AYA cancer patients

Barriers:

- “No one to talk to”

- Feelings of isolation and guilt, which “impacts ability to make friends”
- Not enough AYA resources available
- Trying to find young adult survivors
- Communication with healthcare team, parents, friends, other survivors
- HIPPA laws are very strict for trying to get other AYA’s connected with one another

What would success look like?

- Increasing survival rates of young people, since rates have not changed in over 30 yrs.
- Increase in clinical trials participation for young adult cancer patients.
- Encouraging young adults to go to their physicians for regular check-ups.
- Combining previously established AYA programs at hospitals with other hospitals who have previously established programs.
- Hosting events on college campuses to raise awareness of the organization
- Making pediatric cancer patients more aware of the future implications of being a survivor

I’m Too Young for This Foundation:

- Volunteer run organization that serves the needs of the AYA cancer survivor population.
- A large portion of the money raised goes towards events for AYA survivors, like “Cancer Happy Hour, Ice Cream Socials, Bowling Socials, etc.” Funds raised also go towards sending Matthew Zachary (the founder) to medical conferences to spread the word about I2Y resources for physicians, patients, and families.

Where to Advertise I2Y Resources:

- o State Registry
- o UNC LAF Center- utilize to get names of other cancer centers across the state who treat AYA’s
- o Childhood cancer camps
- o Kwanis/Key Clubs in the local high schools
- o Google Ads
- o Community College System of NC (<http://www.ncccs.cc.nc.us/>)

I2Y Events from 2008:

Carolina Hurricanes, “Hockey Fights Cancer Night”

Crunk for Cancer event at Duke University

How AYA’s Should Talk to their Physician (Presented by Dr. Daeschner, Head of Pediatric Oncology at ECU)

1. Keep a copy of your medical records to present to physician at first visit. (Patient should be sure to receive records from oncologist prior to leaving their treatment facility).
2. Have the physician review your records before the visit
3. A MedPeds Internist (a physician with 2 years of Pediatric residency and 2 years of internist residency) specializes in 17-20 year olds, is recommended for long-term follow up care when treatment ends vs. a regular primary care physician, who typically has no specialized training in oncology or the AYA age group.

4. As a childhood survivor, find a medical home before leaving the treating oncologist. The oncologist should directly send medical charts to the primary care physician/MedPeds Internist where the patient plans to be treated at home.
5. Patient must aggressively pursue their quality of care with their attending physician once treatment ends to keep up-to-date on healthcare needs.
6. Consistency of follow-up is necessary for the AYA population

Other Resources for AYA's:

- PlanetCancer
- Lance Armstrong Foundation (Young Adult Alliance)

Caring for the Caregiver

Intended outcome or goals

- Learn how to take care of yourself
- How to care for self
- Take care of yourself 1st so that you can take care of others

Barriers

- the lack of support in small town across the state (rural areas)
- no one to talk to

What needs to be done?

- the creation of more support groups for caregivers
- increased awareness of the Medical Leave Act
- utilize caregivers, survivors, faith/religious community (pastors, priests) in programs that involve the caregiver
- the creation of more laws that protect caregivers by providing time off (paid leave, ability to maintain employment)

What would success look like?

- Healthy Caregivers

Psychosocial Issues

Group Issues

- 9 year male lung cancer survivor says that only his body was treated not his mind; he is constantly worried that the cancer will come back
- "I don't know that I am a survivor, I've survived so far"
- The participants are seeking wholeness, tiring to find ways to cope with diagnosis, treatment and then with life after
- Some participants identify that they do not like the term survivor. How does anyone know if they have survived yet? Its not over, they have to live with it everyday.
- Surviving is the mountaintop, how do you help people in the valley?
- They do not see themselves as survivors they see themselves as thrivers. They are on the cancer journey.
- See survivor label as a way for caregivers to have closure.
- This session is not the norm. People do not generally sit around and talk about life after the treatment and how it the ordeal has affected them mentally.

- Many have therapists and take anti anxiety drugs when they do to their follow up visits.

Resources

- Anticancer: A New Way of Life by. David Servan-Schreiber
Helpful book about nutrition and psychosocial issues that effect people living after Cancer
- Dana Jennings NY Times prostrate cancer series very helpful.
- End of Life session need to be included in next year's summit (information would be helpful to those in attendance).

Take home message

- Relay the message to your doctor that he needs to be telling his patients about the resources and help there is available to treat the whole patient.
- 75% of patients took advantage of psychosocial services when Dr. advised it as opposed to 15% that were not told.
- Survivorship thing is being beat to death. There needs to be more definition for groups.
- Survivors do not always fit in the Peds group or the elderly. Issues and concerns are different. Groupings need to be made based on current age, sex, and how long they have been cancer free to really be successful at supporting the patient.
- It is hard to find your niche.
- Dr.s need to be upfront, clear and honest with patient. If the doctor says slow growing but it isn't that is a disservice to the patient. He should not sugar coat the news because the patient is going to take what he says as gospel and not listen to family members.
- Dealing with being dependent when you are used to being independent. Being honest with your friends and family and letting them help you.
- Communicate with your family. If they call and visit a lot after they find out and then you notice that the calls and visits slow down because you are getting better, let them know that you liked it when you talked more and that does not have to stop now that you are better.

Common themes among the session discussions (**waiting on the notes from others)

**11:00 am session – 23 participants

** 2:15 pm session – 14 participants

still waiting on notes from a couple of people

Evaluation: Some stats of the Summit follow:

- Seventy-two percent (72%) of those who completed the evaluation survey did not attend last year's summit.
- Of the 300 participants who attended the summit,
 - 56% were cancer survivors.
 - Caregivers made up 15% of the participants, and
 - Health professionals accounted for 23%.
 - Six percent classified themselves as other.
 - Sixty-seven percent felt that the activities met their expectations
 - 56% felt that the broad issues of Survivorship were well covered.

In addition to the summit evaluation, a Survivorship Assessment Survey, developed by the survivorship work group was given to participants. The results of the survey are being analyzed by UNC Lineberger Cancer Survivorship Program and will be shared when the results are released.

The summit planning committee held a follow up meeting via conference call to discuss the pros and cons of the event. Some of the suggestions made include:

- begin planning earlier to secure sponsorships
- continue the 2 day track, however move the days to Friday - Saturday
- offer CME's for professionals
- identify cancer types; allow time to network
- increase survivorship participation
- include a survivor tribute (bell ceremony, etc...)
- include more survivors in planning process

2009 Survivorship Summit Evaluation Summary

	Yes	No
Did you attend 2007 Summit?	11%	84%
Did you attend 2008 Summit?	23%	72%

How did you hear about the Summit?
NCCC program staff, Rachel Urban Survivor's Reception in Wilmington; UNC Hospital; radiation dept; email/Advisory meetings, Pitt Partners for Health & Cancer subcommittee, Gordon Cole, Katherine Lassiter, Duke Patient Support Group, Leo Jenkins Cancer Center, through the Sisterhood of Hope Cancer Support Group I help run mail, Drumstrong, Pink Team Luncheon in Conover NC, Kenisha & Rachel, Attended session last year, Linda Rohret, Walter Shepherd, Mrs. Gwyn Sandlin, breast navigator at CCH, Avila Allison 252-215-5225, Colleen Coda, support group, Last year's event & invitation, At various meetings, email, I'm too young for this via facebook, an email, Rachel Walton & mail, From my support group my daughter, mail from Kenisha, from previous meetings, Avila, Attended last year's & received direct info, Nurse Manager, joint meeting with sister to sister, a past attendee told me, my friend, I came last year, Cancer Support Group Laurinburg NC, Flyer, Cancer support group Laurinburg, Email invite, Community Advisory Committee through Hope Works, Comp Cancer, Doctor referred last year, at duke, email serve on workgroups, UNC Chapel Hill Staff, Save our Sisters, Pitt Partners for Health email flyer, Listserv, Paula - Camp Dove @ Pine Knolls Shores, Friend, co worker, letter, Lorie Perry, Nash Co ACS, Cancer subcommittee email, Catawba Breast Cancer Coalition, Another Cancer survivor, NC DPH, newspaper, co-workers, Letter invitation, Support Group Sister's Supporting sisters, Nurse Manager, Avila Physical Therapist, Greenville, Friend, newspaper, from our church parish nurse, Zimmer Patient Navigator, Marion Hodges, Through SMOC, My support group at Duke Raleigh, Cape Fear Health policy Council Meeting, Wilmington NC, Clifton Langley

	Excellent	Good	Average	Fair	No Response
Did today's activities meet your expectations?	67%	22%	6%		4%
Do you feel today's meeting will be beneficial to you?	66%	25%	5%		3%
Were the broad issues of Survivorship covered?	56%	24%	11%	1%	8%
Were the provided information and materials relevant?	66%	23%	5%	1%	4%
Meeting Facility	72%	22%	1%		5%
Lunch/Snacks	55%	34%	7%	2%	2%
Overall organization of the Summit	69%	18%	4%		8%
Quality of the audio visuals (PowerPoint, slides,etc)	68%	24%	2%	1%	4%

Quality of the materials provided	74%	19%	1%		6%
Caring for the Caregiver	32%	64%	5%		
Adolescent and Young Adult Survivors	75%	25%			
Cognitive Functions	76%	24%			
Sexuality and Intimacy / Self Esteem Body Image	41%	54%	5%		
Prostate Cancer in NC	58%	33%	8%		
Navigating Mountains of Financial Bills and Woes	53%	13%	33%		
Pain and Palliative Care	70%	20%		10%	
Getting the Most Benefit from Your Doctor's Visit	72%	28%		1%	
Psychosocial Issues	78%	22%		1%	
Physical Activity and Nutrition	64%	36%			
Patient Navigation (more discussion)	40%	40%	20%	2%	
Did you learn some new things?	38%	16%	0%		46%
Was the speaker to the point to the topic of discussion?	46%	13%	2%	1%	39%
Presenter's knowledge of the contents	44%	9%	2%		44%
Presenter stayed within the time frame	45%	15%	1%		39%
Did you feel your thoughts were concerned during the session?	44%	12%	3%		41%

<p>Is there anything you like to be changed?</p> <p>Acoustics - hard to hear in the back, when registering make sure you ask permission to publish the person's address & phone number, this could be a legal problem, keep up the good work, Provide objective (clear objective) for summit to address who it is designed for. Possibly have two tracks one healthcare provider, one survivor then have joint sessions to share ideas more non sweet items for breakfast & break, find ways to market summit to more cancer survivors and/or get treatment centers to inform their patients, No, I enjoyed learning from the survivors, reimburse for mileage if you do not stay over night, maybe one day unless continuing education, How about a wall of paper where we can write the names of friends and other family members with cancer, You had excellent presenters - try not to have great performance while people eating maybe have some doctors or nurses talk on specific cancers and what to look for signs & symptoms Overall, I really enjoyed! have some written questions so more questions can be answered at each session esp. breakout on Getting the Most benefit out of your Dr. Visit, Nothing, it was well organized & met my expectations as a first time attendee, Don't really need two days unless including continuing education, provide topics across cancer continuum including, end of life topics, use different name tags one that go around the neck; menu for lunch/dinner, choice; Is there anything you like to be changed? The individual breakout sessions were too long, I would have liked to attend more sessions in shorter periods of time, and Can we have presenters who are not all breast cancer survivors? thank you for rotating around the state, you could have a lighter lunch and still have adequate food, put in a 30 minutes break, Y after lunch, make supper 30 mins later, make clear when presenters have a presentation to name the session as such, Open forum should be held at beginning of Summit, this way people can interact with others in a more identifiable way. Forum was wonderful and it had lost of participants discussing their stories afterward.</p> <p>In the meeting it was not participation encouraged for other participants, repeat second day workshops again in afternoon way too much downtime, More interaction between groups of patients like the breakouts that occurred the last two years, that would be a benefit in learning how other people with different cancers deal with similar problems Just get the news out faster to other areas, I can't, it was very well planned, Find a way to make it easier for those, still weak from chemo, Thurs from 0200-2000 way too long walking distances between session seemed far, no planning for the weak, Have T-shirts made with the NC Cancer Survivorship Summit Logo, very good overall program, well organized, Jobs available in this field, shorter break out sessions, Everything was wonderful, No-time is good, plenty of time for networking, checking out exhibits. Topics good, need more survivors here in addition to the relatively large # of attendees from various organizations. Suggest flyers placed in Cancer Centers, not emailed 3 days, No, it was difficult for me to take in everything there was so much going on so many people to meet</p> <p>Comments:</p> <p>I'm leaving this summit with a good feeling about the courage, and the strength I received, Please add workshop/break out session description to agenda to help participants make a selection, A little hard to</p>

watch the speakers/entertainment while eating if your back was to the stage, would have been nice to chat with folks at the table, Excellent summit, keynote speakers were outstanding good way to start off the conference, Notice of event needs to be more available I didn't hear about it until a couple of weeks ago.

Breast & prostate test were emphasized; no one mentioned the most dreaded test colonoscopy, Thanks great entertainment, The networking opportunities were phenomenal, Could not find out how/where to get picture taken for "Faces", do not use or print email/addresses without prior permission from "owner"; Fantastic ready for next year, Roger, Kathy, Marcy and Barbara were all super, repeat open forum what a great project and all the people that did the project were just friendly & so nice, Walter you and Kenisha were great, May God keep you both close in his heart, Excellent Program, presenters, food, entertainment, More open forum time, all was fantastic, very encouraging & gives everyone joy & hope, As a professional in the cancer area I thought this was helpful but for me with family spouse with cancer it was a very soothing event, thank you, Overall this summit is a wonderful learning tool for those who have not had cancer, Nutrition info right on time! Variety of resources amazing there were several new resources that I hadn't realized were available to help people with cancer. Somehow this has been the best summit ever and it's still day 1, meeting rooms cold, chairs to short, wireless static on mike is distracting, I would like to have an exhibit table & present next year, I had the best time I look forward to next year, I really enjoyed this, It was my first time but it will not be my last, The entertainment programs have been outstanding, you have done a wonderful job of getting survivors & families involved in identifying issues & solutions, Great summit even better than last year. Excellent performers/entertainment, keynote, lunch & dinner, Excellent summit, Make sure breakfast is more than sweets and breads everything else was great. The meeting speakers are very informative and welcomed participants comments & suggestions, Comments, Ready for next year, hanging nametags, Love it can't wait till next year, Generally very good, continue to stress a deeper level of research instead of just an introductory presentation Keep doing topics to bring in the younger, I very much appreciated the opportunity for scholarship. Summit was great, Helpful & excellent presentations, I enjoy the sessions, hope to be a part of next year, Wonderful summit, I pray that I will be able to come again, Thanks, Wonderful Caregiver workshop/Absolutely wonderful lunchtime speakers Mary and 2 beginning speakers, Please advertise to DPH Campus several of us have had cancer Thurs night speaker was great too, You will have to do a lot to top this summit - thank you for all you do, Both very informative & helpful, Limited Palliative Care left me wanting & needing more deal with pain more, Such a great bunch of truly sincere and caring survivors and instructors, It was a great summit. I thoroughly enjoyed it. The speakers were terrific. The staff did an excellent job in planning; A lot of planning & preparation went into this wonderful summit, great programs & entertainment. Very informative sessions, look forward to sharing with new friends at next year's summit, Consideration for weak participants, open day way too long, First time attending, it's been a great day, I am so happy to attend. I wished more people had listened to me to come, Cancer and Nutrition was very interesting and helpful, Speaker @ lunch on Thursday wonderful, I truly enjoyed this summit, this was just enough mix of entertainment & education, Each session was layed out very professionally. I was moved from all of them, everything was said and done, The open forum was inspirational and a source of strength, Loved the tables set up with information, interesting to understand that young adults & adolescents often fall through the cracks so far as support & organizations, Ms. Starkey allowed question & comments during presentations. Her answers were easily understandable, Some breakouts for medical information TX or DX, Thank you for the invite, looking forward to next year, God Bless, It's OK to cry and always laugh, shorter break outs so you could go to more of them. Did not get to go to the ones I wanted to, no time, Good job, Keep Open Forum have a cheerleading squad, Mary Lou Blakeney will lead, would like to see more generational, gender, racial and cancer type, Thank you

Suggestions:

We need to laugh more; Thursday's entertainment was too heavy; Lymphedema – I would be interested in presenting at next summit or find someone (CLT) in Charlotte to speak – Allyson Daugherty; more info @ upcoming meetings, events for survivors, presentations given by survivors or a Q & A session with care givers/professionals doing the asking; yoga or other exercise session; keep open forum, maybe do one on day 1 and then another at end use your contact list from events to reach everyone by mail or phone; A session on a side effect of breast cancer, lymphedema; Longer open mike; Skin cancer, more on patient/survivor resources, financial assistance/estate planning, writing therapy, art therapy, end of life issues, laughter therapy; Find a way not to waste or have to pay for the meals when folks don't show up for dinner; End of life issues explained; more open forum time and good entertainment like today's; Always

grateful and amazed by survivors who share their experiences and triumphs; coping skills, spirituality, helping kids cope/kids & parents with cancer; Financial help when you don't have insurance/signs and symptoms of prostate, breast, stomach, etc...cancer; Cancer? Now what/continue; God grant you Peace when storms arise on your journey! Laughter yoga, let's have a dance after our dinner reception; the role of faith in cancer diagnosis/treatment and survivors; healing therapy – acupuncture, massages, hypnosis, etc., Suggestions for future meeting topics; pharmacists to talk about medicines that we have taken and about side effects that follow, how to partner with local community screening clinics; how to reach the homeless; add yoga, end of life; can we do living will that can be notarized at next year's event? All next year need to be shown Google Health, do Google Health for the whole group or repeat small groups; follow the suggestions of the evaluations; thyroid cancer survivor issues; it was well planned and speakers were fantastic; special, special thanks to Kenisha; a special thank you to all the workers esp the ones not in the spotlight; why were there not 2 screens in the large meeting room? Round tables only let half the speaker and another screen would have made it visible to all those around a table, coping – future, none; do Getting the most benefit from your doctor's visit for the general session; sheet of quotes from tables; more on children with cancer and their families; You seemed to cover most everything.

Budget

As with the previous summits no registration fee was charged. To defray costs for the survivors, meals were provided both days. Thursday included breakfast, lunch, and dinner; and breakfast and lunch were provided on Friday. NCCCP staff secured additional funding for this year's event from wonderful sponsors and partners. Most of the funding secured was used to provide lodging scholarships to 55 survivors and their caregivers for 100 nights (\$12,317.00). Daniel's Tours provided free transportation to cancer survivors in Wilmington, NC to and from the event. All incentives, raffles, and/or promotional materials were provided as "in-kind" donations by sponsors and exhibitors (36).

Conclusion

The North Carolina Comprehensive Cancer program needs to continue to work towards increasing survivor participation as well as partnerships as the summit moves across the state. All cancer centers and affiliates should be involved in providing professional expertise, support, and promotion of the coming year's summit. Increased participation should be sought from counties that were not represented at this year's summit. The Program needs to provide opportunities for NC cancer survivors to claim ownership by allowing greater participation in the planning of future summits through the partnership work groups or support groups across the state. The NC Cancer Plan's sections regarding survivorship should continue as a guide for the annual events. Work on upcoming summits should continue the processes of achieving the goals, objectives and suggestions offered at this year's meeting. Adoption of the NC Cancer Plan as a document to assist survivorship needs to be facilitated to assist survivors, caregivers, advocates, and health professionals across the state.

Special Thanks to our Partners, volunteers, Survivorship Planning Committee, and NC Comprehensive Cancer staff for their tireless efforts in making this event a success.