PanCare - European Network for Survivors of Childhood and Adolescent Cancer

Alex Brownsdon

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survivornet1@yahoo.co.uk

SurvivorNet Facebook page
Twitter page; @SurvivorNet1
Overview

• History and Background
  • Need for a Survivors’ Network
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• SurvivorNet Currently
• Challenges
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History & Background

• Long term need for a survivors’ network
  • Connection with international parent (ICCCPO; www.icccpo.org/) and survivors (ICCSN) groups
• SurvivorNet - officially founded September 2010 as part of PanCare (www.pancare.eu)
• PanCare - A European network of professionals, survivors and their families established in October 2008 to ensure that every European Survivor of Childhood and Adolescent Cancer receives optimal long-term care
• Invitation to 4th PanCare meeting, Newcastle UK October 2009 - need for survivors’ network expressed
• 5th PanCare meeting, Paris April 2010, name ‘SurvivorNet’ created
History & Background

• 6th PanCare meeting Mainz, September 2010 - evidence presented to support the need for SurvivorNet

• Findings regarding the available on-line support for survivors were presented (researched in English, German and Greek);
  • Range of support widely variable and sporadic - no standardisation
  • Many survivor groups implemented an age limit of around 24 years
  • No clear differentiation between a ‘Cancer Patient’ and ‘Cancer Survivor’
  • Not **ONE SINGLE** support network which brought together both survivors and professionals from across Europe to improve the long-term outcome of adult survivors of childhood and adolescent cancer (especially for those over the age of 25 years)
“…Welcome to Planet Cancer, a community of young adults with cancer...that age between ‘paediatric’ and ‘geriatric’ where no one knows whether to give you a lollipop or a serious talk about your fibre intake!..” (www.planetcancer.org/).

“...We realised that this 25 to 30 year old age group were becoming a ‘lost tribe’...no longer able to join in with the services available for young people with cancer...but simply missing out...” (Youth Cancer Trust www.yct.org.uk/).

“...In order to effectively address the needs of Survivors, the focus must shift to a continuum of care that lasts a lifetime...” (www.beyondthecure.org/).
SurvivorNet Aims

• SurvivorNet ‘as a network’ was officially founded in Mainz 2010

• ‘SurvivorNet’ was created with the intention to benefit childhood and adolescent cancer survivors over 25 years old, from across Europe and potentially Internationally

• SurvivorNet aims to be the GOLD STANDARD in providing support for adult survivors of childhood and adolescent cancer, empowering survivors by providing access to a wide range of valuable resources and information sources through ONE comprehensive network
Existing reliable resources

Parents groups
Policy

Web based information & support

Guidance
Research

Other information

Survivors

SurvivorNet

Parents & families

Survivor/ cancer organisations, networks & groups e.g. ICCSN etc.

Web forum
Professional organisations

Area to post updates, news & publications

Interactive and Collaborative

Survivors

Professionals
SurvivorNet Aims

SurvivorNet ultimately aims to facilitate;

• An accessible website and web/communication forum
• Survivors’ meetings and conferences
• Advice and information on education and employment
• Advice about Life insurance and mortgage
• Information on follow up care and late effects
• Information on travel insurance
• Advice regarding disability and healthy lifestyle
• Promotion of formal mentorship programmes for childhood cancer survivors
• A platform for international collaboration, (ICCSN)
SurvivorNet Currently

- Communication with European and International survivors
- Promotion at PanCare and other European and International meetings
- Facebook and Twitter pages created in 2012
- New website in process of being developed and will include the following areas;
  - ‘About SurvivorNet’ – History and background
  - News and events – Will be updated regularly with new information
  - ‘Associates’ – Links to professionals and organisations
  - Resources – Links to other websites and useful information
  - Links to Facebook and Twitter pages – Acting as the communication forum
Challenges

- Lack of time and commitment regarding support in development of the website and promotion of SurvivorNet
- No funding to develop the network and resources e.g. the website
- Resistance
Where next?

• Website completion and promotion
• Solid commitment and help with the website - on going maintenance
• Promotion of Facebook and Twitter pages in conjunction with website
• Promotion of SurvivorNet in general
• Involving and reaching more survivors
Acknowledgements

• PanCare for the opportunity to develop SurvivorNet
• All those who have already contributed to the development of SurvivorNet
• Thank you to everyone who has supported us so far