

Resources and links - USA & Canada

Last Updated Wednesday, 28 October 2009

WebCafe has separate pages for resources specific to:

Resources in Europe

caregivers/end of life issues

ostomates-on and off-line supplies, support and info

clinical trials

alternative-complementary medicine

financial help/resources

Patient's Advocacy - US:

BCAN - Bladder Cancer Advocacy Network

ABLCS - American Bladder Cancer Society

Patient's Advocacy - Canada:

CBCAN - Canadian Bladder Cancer Advocacy Network

Researching Your Cancer

CancerGuide <http://cancerguide.org>

Steve Dunn's very valuable resource to help those just beginning their search. Valuable info and links, a crash course on "Cancer 101": "The Pros and Cons of Researching Your Cancer: Researching isn't for everyone. Is it for you? Find out here!" For some great tips on how to search the medical literature, researching rare cancers, as well as info about clinical trials, alternative medicine and more. This is a site developed by one who's been there, to help those just beginning their search.

For help without the computer, for US citizens: Cancer Information Service (CIS) Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

The American Cancer Society <http://www.cancer.org>; The website from the ACS provides help and resources to patients and caregivers all over the US. They also have a toll free number, 1-800-ACS-2345; Information Specialists are available 24 hours a day, 7 days a week.

National Cancer Institute - NCI's primary web site; contains information about the Institute and its programs. Also includes news, upcoming events, educational materials, and publications for patients, the public, and the mass media

NCI ClinicalTrials; <http://cancer.gov/clinicaltrials/>

NCI's comprehensive clinical trials information center for patients, health professionals, and the public. Includes information on understanding trials, deciding whether to participate in trials, finding specific trials, plus research news and other resources. More info about trials on Webcafe

Entrez-Pub Med <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=PubMed>

Pub Med is a search and retrieval system that integrates information from databases at NCBI, including Medline, or the National Library of Medicine. The 'related articles' option can get you deep into cyberspace. Typing the PMID or UI number of a published article in the search box will pull up the abstract.

Medline Plus <http://www.nlm.nih.gov/medlineplus/bladdercancer.html>

Excellent compilation of bladder cancer info, as well as a link to a list of abstracts of the most recent research being done around the world, current clinical trials (US) and much more

MD Anderson <http://www.mdanderson.org/diseases/bladder/>

M. D. Anderson Cancer Center Bladder Cancer Information - Read about bladder cancer research and treatment news from experts at M. D. Anderson. The site also provides basic bladder cancer information and support resources to help patients both during and after treatment. See their 'treatment guidelines'.

Mayo Clinic <http://www.mayoclinic.org/bladder-cancer/>

Bladder cancer research, diagnosis, and treatment information at Mayo Clinic. This site also includes links to clinic trials available through Mayo Clinic, as well as information on specific treatment options.

Oncolink <http://oncolink.upenn.edu/disease/bladder/>

For basic info about TCC, NCI/PDQ patients' and physicians statements, treatment options per stage, and CancerLit access to the last two years of published articles pertaining to bladder cancer, all linked to from this 'user friendly' page. Includes 'Useful Introductory Resources', helpful things such as 'How to

communicate with your doctor”, tips from a physician.

Medline Plus/dictionaries <http://medlineplus.nlm.nih.gov/medlineplus/dictionaries.html>

Many links to medical dictionaries and glossaries

CancerWEB <http://cancerweb.ncl.ac.uk/omd>

Simple and extensive online medical glossary. A UK site.

Medscape <http://www.medscape.com>

Register (free) with 'Urology' as your homepage and you won't be sorry, lots of great articles updated regularly. Mescap is great resource and is getting better all the time.

United Ostomy Associations of America <http://www.uoaa.org> This is a volunteer-based health organization with over 200 affiliated local support groups in the US, dedicated to assisting people who have had, will have, or are considering having intestinal or urinary diversions. National UOAA 1-800-826-0826 can give names and numbers of US support groups as well as groups in Canada and internationally.

The Urologychannel <http://urologychannel.com>

Excellent information site which features a forum where you can leave questions which may then be answered by an expert.

MedicineNet.com A good, patient-friendly site explaining all the basics of blca

The Internet Drug Index <http://www.rxlist.com>

Name speaks for itself!

The Wellness Web <http://www.wellweb.com>

Fantastic site with a sensible mixture of information on mainstream and complementary medicine.

Treatment Guidelines - online courses

The European Ass. of Urology: Guidelines for treatment of bladder cancer

The European School of Urology : Management of Superficial Bladder Cancer Online course

American Urological Ass.: Patient's Treatment Guidelines for superficial, non-muscle invasive bladder cancer, published 1999

About Superficial Bladder Cancer: external sites from expert uro/onc Michael O'Donnell, MD, U of Iowa

Bladder Cancer Research Institute

Biologic Therapy in Bladder Carcinoma

Physician's Protocol- BCG+Interferon Alpha for Superficial Bladder Cancer

Projects in Knowledge: New Prospects in the Treatment of Superficial Bladder Cancer

Dr. Donald Lamm- BCG Oncology, one of the US' top uro-onc and BCG expert

The Moffitt Cancer Journal: An excellent series of articles about bladder cancer <http://www.moffitt.usf.edu/pubs/ccj/>

Vol. 7, No.4 July/August 2000 Bladder Cancer

Vol. 9, No. 4 July/August 2002 Urologic Cancers

Vol.7, no.4:Vol. 11, No. 6 November/December 2004 : Genitourinary Tumors

RECOMMENDED READING

Bladder Cancer, Urostomy and Impotence, by Roni Olsen. Bladder cancer advocate and volunteer Roni has donated her book free to the public. The book is in pdf format and may take a minute or two to download.

The Guide to Living With Bladder Cancer Mark P. Schoenberg, M.D., F.A.C.S. and the Faculty and Staff of the Johns Hopkins Genitourinary Oncology Group. Easy to read guide for patients and family: symptoms, diagnosis, treatments, by the director of urologic oncology at Johns Hopkins, one of the very top institutes for uro/oncolgy in the US.
http://www.press.jhu.edu/books/title_pages/2644.html

This link takes you to Johns Hopkins University Press, where you can order the book online.

100 Questions and Answers About Bladder Cancer Pamela Ellsworth, Brett Carswell, Jones and Bartlett Publishers;
Medical texts: <http://medicine.jbpub.com/>

Choices in Healing (available free online) Michael Lerner's excellent book on just about everything out there pertaining to alternative/complementary cancer treatments. Helps one to make a more informed choice, by giving all the angles. A critical look at mainstream oncology has gotten him on the bad side of Quackwatch and the NCI, but for me and many others, his book is an oasis of reason in the terrifying world of cancerland.

Siegel, Bernie S. Love, Medicine and Miracles. Harper & Row, New York.

A classic book on self-healing through mental techniques.

Siegel, Bernie S. Peace, Love and Healing. Harper & Row, New York.

Follow-up to Love, Medicine and Miracles.

Weil, Andrew. Spontaneous Healing. Ballantine Books, New York.

"How to discover and enhance your body's natural ability to maintain and heal itself".

Dr. Andrew Weil <http://cgi.pathfinder.com/drweil/> is now online with a cyber community.

Simonton, O. Carl. Getting Well Again. Bantam Books, New York.

Old, but important book. This was the book that first made people aware of the importance of mental techniques and support groups in healing.

McKay, J. Hirano, N. The Chemotherapy Survival Guide. New Harbinger Publications, Oakland CA.

A self-help book with a lot of useful advice for getting through chemotherapy.

Coping Magazine

Cure Today Cure, online as well as free print subscriptions, articles, news and support for cancer patients and their families.

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