

Web report The ARDS Support Center

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Website The ARDS Support Center

URL <http://www.ards.org>

Cost Free

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The ARDS Support Center (developed by Ken Jonah, an acute respiratory distress syndrome [ARDS] survivor, and supported by donations from ARDS survivors and ARDS victims' families) is a website devoted to providing relevant medical information and emotional support to survivors of ARDS and to patients' families. In reviewing this site, we browsed through the online offerings and assessed the information provided as well as the user interface.

The website begins with basic information on ARDS in a link entitled 'Learning about ARDS'. This portion of the website is devoted to providing information in layperson's terms about what causes ARDS, basic pathophysiology, and current treatment strategies. It demystifies the medical jargon routinely used in the intensive care unit (ICU) by including a glossary of terms and a Frequently Asked Questions page. Additionally, there is an entire section dedicated to both established and novel therapies currently available for ARDS. Explanations are offered on such topics as nutritional therapy, inhaled nitric oxide, extracorporeal membrane oxygenation, and prone positioning. There is even a link to an article in the *New England Journal of Medicine* reviewing ARDS; a copy of the Adobe Acrobat® utility (for viewing .pdf files) is available for download. The authors have made a clear attempt to keep the information at the layperson's level, and they have succeeded in simplifying relatively complex topics to the extent possible. Information is also provided on the many physical, cognitive, and emotional problems that can be expected after discharge. Additionally, the authors describe

what rehabilitation is like and offer advice as to how to benefit most.

The website offers more than just information, however. The Pen Pal Circle is an e-mail support group for ARDS survivors and their families. Here, patrons relate their stories, offer support, and ask for help with the complex and multidisciplinary recovery after discharge from the ICU. We found especially notable the offerings on how to cope with the vivid dreams patients often have post-ARDS, as well as patients' answers to the question 'Will I ever be normal again?' Although this section may be supportive for patients after discharge, the Pen Pal Circle's frank accounts by ARDS survivors are vivid and might be upsetting to families with loved ones currently in the ICU. Links are provided to other related websites including, a site for 'grief and healing'. Specifically, information is included regarding the National Institutes of Health's ARDS network and individually on centers participating in cutting edge ARDS research.

On the whole, the authors have done a nice job of providing 'information, education, care and support for patients, survivors, family members', as outlined in their Mission Statement. The site is solely directed at ARDS and does not cover any other critical care topics, even those possibly seen in conjunction with ARDS. The site is generally easy to navigate, although the search engine was not very helpful. Each activated link on the site opens an additional browser, which can become cumbersome after a while, but overall the

site is well designed and free from obvious commercial bias. We have, in fact, been referring our patients' families to this website for some time, and we have received nothing but positive feedback. We would certainly recommend this website to patients and their families.

Best features

The site presents medical information in layperson's terms, and the Pen Pal Circle allows survivors and families to connect with each other.

Worst feature

The propagation of new browser windows with every activated link becomes cumbersome and clutters the desktop.

Wish list

Information on other diseases often encountered in conjunction with ARDS (e.g. severe sepsis and the multiorgan dysfunction syndrome).

Other links:

The ARDS Foundation of Illinois –
<http://www.ardsfoundationil.com/>

Another site with extensive information on ARDS for patients and survivors; it also offers support groups and survivor stories.

The ARDS Clinical Network –
<http://hedwig.mgh.harvard.edu/ardsnet/>

A resource describing the US National Institutes of Health's ARDS network and outlining the network's goals. It also contains a Frequently Asked Questions section on ARDS, as well as news on completed and ongoing ARDSnet trials.

American Lung Association® Fact Sheet: Adult (Acute) Respiratory Distress Syndrome (ARDS) –
http://www.lungusa.org/diseases/ards_factsheet.html
A simple and short page providing ARDS definitions from the American Lung Association.

Competing interests

None declared.