

This is a roundtable of people who operate psoriasis advocacy web sites. There are many dozens more of us – so those of us sitting up here today consider ourselves REPRESENTATIVE.

For working purposes, we'll start with an understanding that "advocacy" means communication toward these three things:

a cure ... more equitable access to treatments ... and further understanding for everybody about psoriasis and living with psoriasis.

It has been suggested that more collaboration between psoriasis advocacy web sites might result in more effective advocacy at large. Put another way, the outcome of a collaboration might be greater than the sum of its parts. We might move science closer to a cure ... help more people find ways to get the medicine they need ... and help overcome public fear of our condition.

Today we want to explore these suppositions and ways we might make them come true. Please pitch in and help with questions and comments. Raise your hand and, when you're called upon, please speak loudly as all of this is being recorded for posterity by a stenographer.

Before we get started, let me thank GENENTECH for their sponsorship of this workshop and the concept of independent psoriasis web sites working collaboratively. Now, let me quickly introduce you to my colleagues at this table, in alphabetical order ....









Every national non-profit membership organization learned in the 1990s that they were going to have to have a web presence to thrive in the immediate future.

Fortunately for us, the National Psoriasis Foundation figured this out relatively early. With the help of some friends – one of whom will be introduced here in a second – the Foundation got on line in the mid 1990s. Their site and visitor base has been growing ever since.

(next)



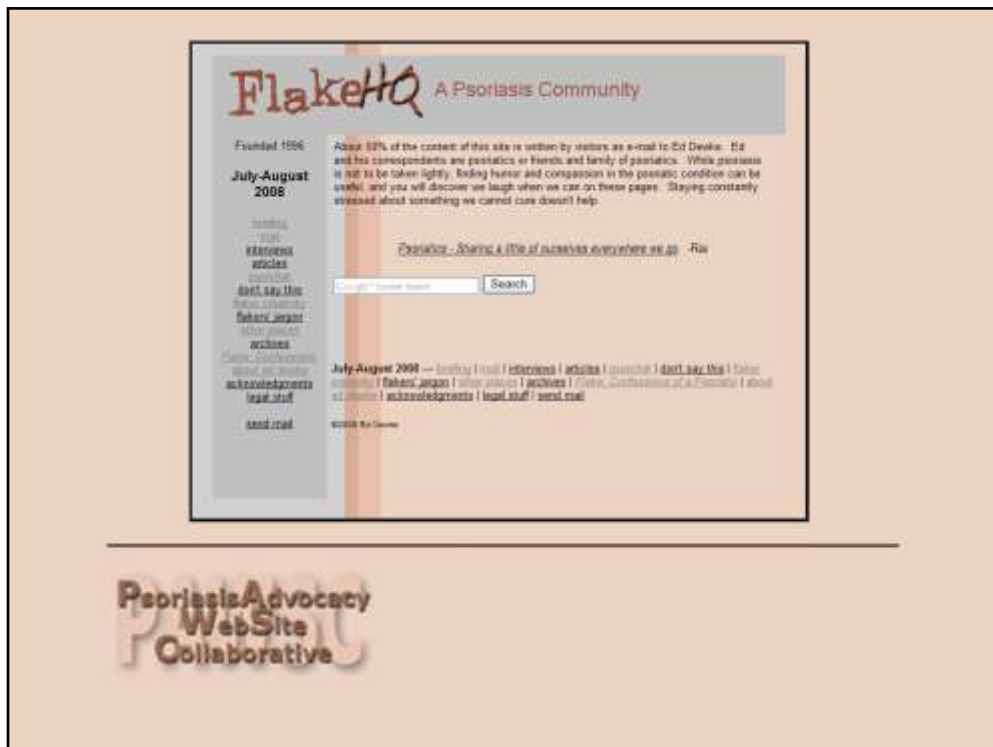
Catie Coman is the Director of Communications for the Foundation, a position that includes the operation of psoriasis-dot-org. The Foundation's web site really is top dog on the Internet. All of the rest of us rely on psoriasis-dot-org for information that we freely link to and talk about.

I think of psoriasis-dot-org as the flagship in the fleet. The rest of our sites are other kinds of boats with other kinds of tasks. But we are all participating on the same side in our human war against this disease.

One more quick peek ... And with Catie's permission....



An all new psoriasis.org is being unveiled in a few months. Catie has shared with us a mock-up of the new home page. Stay tuned!

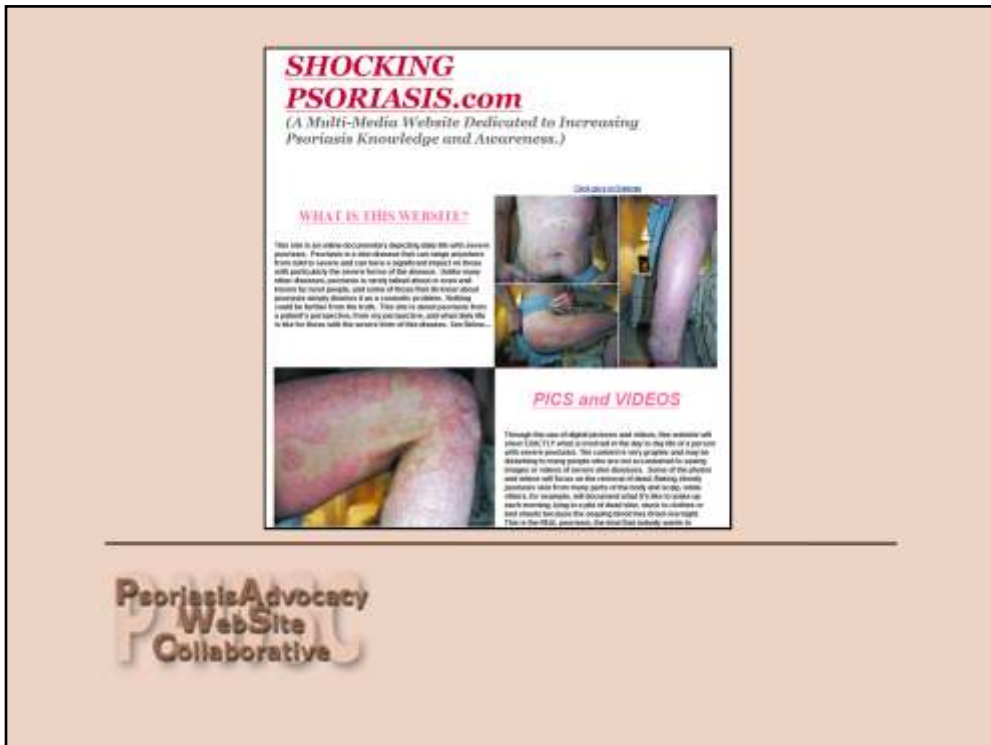


I created FlakeHQ in 1996 to sell a book – my sometimes humorous memoir about getting and living with psoriasis. I also wanted to start an online community.

Book sales dwindled quickly while the community grew steadily and continues to grow.



Today the site is all about community. As far as I know, FlakeHQ is the only psoriasis advocacy site that publishes fiction, poetry and art photography. And over 1,300 email exchanges are archived there.



Michael Harnick launched Shocking Psoriasis-dot-com in the Fall of 2007. It is unique among independently operated psoriasis sites. Not surprisingly, awareness of shocking psoriasis-dot-com spread like wildfire.

Through pictures, video and very few well-chosen words, Harnick makes life with severe psoriasis abundantly clear.



Shocking psoriasis dot com spits in the eyes of all those who have the ignorance and audacity to call psoriasis a “cosmetic condition.”

Some day psoriasis WILL BE cured. Then, shocking-psoriasis-dot-com will be a cultural artifact, a piece of digital archaeology, and I take great satisfaction in feeling that, when that time comes, this site will still be important – as history.



Ed Reiss – the proprietor of the Psoriasis Online Toolbox – built the National Psoriasis Foundation’s first web site in the mid 1990s. He also built the web site for the International Foundation of Psoriasis Associations, known also as I-F-P-A.

He says he created the toolbox for himself, to support committee work he was doing while on the Board of Trustees of the National Psoriasis Foundation. After a few years of using it and fussing with it, he decided it might be handy for other people who were serious about finding good psoriasis information on the web.



In my estimation, the toolbox is the best source for research about psoriasis. It enables me to avoid “surfing” and drill down directly to the information I need when I need it.

That’s a utility that can only become MORE valuable over time.



PsorChat – a Yahoo Group -- was created by Rob Traister in mid 2001 – seven years ago. Yahoo hosts the group, as they do several thousands of groups, so the technologies required and afforded to PsorChat members are “off the shelf” at Yahoo and Rob does not have to spend a lot of time worrying about them. Which is good...



... Because most of Rob's time as group administrator is spent ensuring the board stays hospitable with a minimum of censorial administration. ....

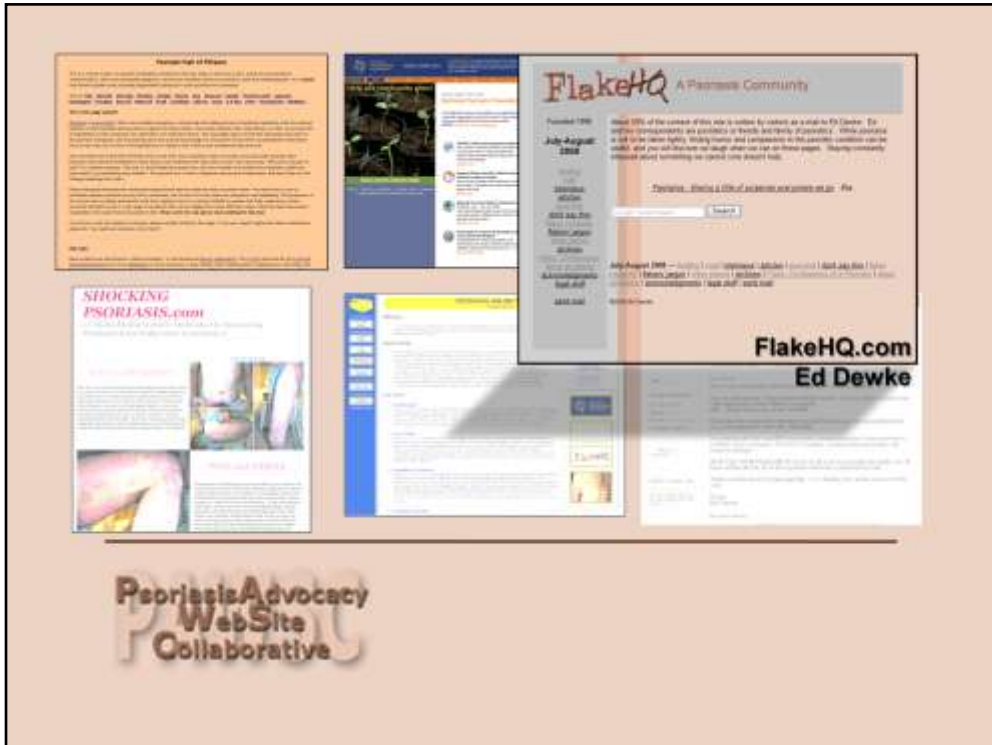


Many psoriasis online groups, or forums, or message boards exist – they come and go with regularity – and a large portion of them are associated with larger web sites. The Foundation, for example, hosts a number of message boards. PsorChat is representative of all of them, but has no institutional connection. For me, it’s like a one-off tavern on an out-of-the-way corner of a modern big city. A haven – of sorts.





... The National Psoriasis Foundation website, represented by Catie Coman.



Ed Dewke here for FlakeHQ-dot-com ...



Michael Harnick's Shocking Psoriasis-dot-com ...



Ed Reiss's Psoriasis Online Toolbox ...



And Rob Traister's PsorChat – A Yahoo Group.



That's today's roundtable. Again we are a fragment of the wide variety of Psoriasis sites on the Internet.

Can I see hands raised by people here who are also associated with psoriasis web sites?  
... (Thank you. We look forward to hearing from all of you.)

In our diversity, we hope to be representative. We also hope that if anything materializes in the way of collaboration, or a consortium, or a collective, other sites – all the other sites -- will join.

The slides\* used during this workshop  
and other documentation  
will be available on  
Tuesday, August 19, 2008  
at:  
<http://flakehq.com/pawsc>

\* Slides archived as a Microsoft PowerPoint slide show.

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These slides and more will become available on this web page as of Tuesday, next week. Of all the other web site addresses you've seen so far, this is the one you don't want to forget, because it will contain links to all the others talked about here, today.

Now, let's get going!

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