

FEATURES

An autoimmune disorder, in camouflage



Experts say Sjogren's syndrome is one of the three most common autoimmune disorders, but few laypeople know of it, and doctors rarely think of it when patients describe its various symptoms

BY JANE E. BRODY
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How can a disease that afflicts some 3 million Americans, 90 percent of them women, be as obscure as Sjogren's syndrome? Experts say it is one of the three most common autoimmune disorders, but few laypeople know of it, and doctors rarely think of it when patients describe its various symptoms.

Medical students, even those in postgraduate training, learn little or nothing about Sjogren's (pronounced SHOW-grins), in which the body attacks its own secretory glands and tissues. Diagnosis can be difficult because symptoms vary widely from patient to patient, and many of those symptoms mimic those of a host of other conditions.

As a result, "this major women's health problem is still largely underdiagnosed and undertreated," said Frederick Vivino, a rheumatologist at the University of Pennsylvania Medical Center and director of the Penn Sjogren's Syndrome Center in Philadelphia.

But Vivino said in an interview that there had been "a dramatic change" in the diagnosis and management of Sjogren's in the last five to 10 years. Although it was originally listed in the National Organization for Rare Disorders registry, recent population studies in the US and in Britain have documented Sjogren's as the second-most common autoimmune rheumatic disease, behind rheumatoid arthritis.

The disorder was first described in 1892 in a 42-year-old man and called Mikulicz's syndrome. But the diagnosis fell into disuse because it seemed to encompass so many conditions. The syndrome was resurrected in 1933 by Henrik Sjogren, a Swedish ophthalmologist, who described 19 women suffering from dry mouth and dry eyes, the most common symptoms of the disorder.

A SPECTRUM OF SYMPTOMS

Lisa Worthington, 43, finally learned she had Sjogren's last December, after six to eight years of confusing health problems.

"Sjogren's is like a chameleon — it causes so many disparate symptoms throughout the body," Worthington said in an interview. "It can seem like multiple sclerosis, stroke, fibromyalgia, Lyme disease, chronic fatigue, reflux and a bunch of other diseases. I've often had to explain it to physicians."

Worthington now runs a marketing and public relations agency out of her home on the Eastern Shore of

Maryland, which permits her to take time off when her health demands it. Before receiving a correct diagnosis and treatment for her spectrum of symptoms, Worthington said, she was told she had fibromyalgia, a reasonable explanation for her chronic muscle fatigue, joint pain and weakness.

"If I had to spend all day on my feet, the next day I had to stay in bed," she said. But not until she awoke one morning with her eyes so dry she could not open them — "the lids were stuck to the eyeballs" — did a rheumatologist suggest Sjogren's.

Though a blood test for telltale antibodies was negative, which happens in 40 percent of cases, the doctor sent her for a lip biopsy at the Sjogren Clinic at the National Institutes of Health, which confirmed his suspicions.

The all-too-common delay in diagnosis, which Vivino said still averages six years, can result in serious complications, including damage to vital organs.

Prompt diagnosis is also important because people with Sjogren's face a 44-fold increased risk of developing lymphoma and must be alert to early signs of this cancer.

CHANGES FOR THE BETTER

Vivino said that although Sjogren's was long thought to be an affliction primarily of white women around the age of menopause, it is increasingly being recognized in nearly all population groups: younger women, women of various racial and ethnic groups, men and even children.

"About 200 pediatric cases have been identified thus far," he said.

Worthington was 37 when she developed symptoms that prompted her to consult a doctor; knowing what she does now, she believes signs were present years earlier.

Two other important advances are the publication in 2002 of internationally accepted criteria for diagnosing primary Sjogren's (the condition can also occur secondary to other disorders), and the development of several medications that can stimulate the flow of saliva and relieve dryness and inflammation of the eyes.

Vivino said there was also growing interest among pharmaceutical companies in biologic remedies.

WIDESPREAD EFFECTS

Sjogren's can affect the basics of daily living and forces its sufferers to adjust life around it.

"I have trouble swallowing,"

Worthington said. "I can't swallow anything without liquid. I always carry a bottle of water with me, long before it was fashionable. Even at night, I have to drink water frequently and, of course, use the bathroom frequently. I often wake up feeling like I never slept."

My stepmother, Sophie Brody, also had Sjogren's. She thought at first she had a tumor because food would become stuck in her throat. Eventually she was unable to swallow anything but pureed and liquid foods. Even to swallow those without difficulty, she had to have her esophagus dilated every three months.

Her dentist was the first to suspect Sjogren's. Her teeth were inexplicably decaying, breaking and falling out, the result of an insufficient flow of saliva to cleanse them. Women who develop Sjogren's in early adulthood often need complete dentures by their mid-40s, Vivino said.

Depression is another frequent component of Sjogren's, often preceding the onset of debilitating symptoms that may make anyone depressed. In fact, doctors at Johns Hopkins Medical Center are investigating various neurological manifestations of the syndrome, including spinal inflammation that can result in a misdiagnosis of multiple sclerosis.

Because Sjogren's affects so many organ systems, other common symptoms and signs include vaginal dryness; enlarged parotid glands, the salivary glands in front of the ears; hoarseness; chronic dry cough; recurrent sinusitis, bronchitis and pneumonia; an extreme sensitivity to cold; dry skin and rashes; digestive problems, including a sensitivity to gluten; thyroid disorder; kidney problems; memory problems; numbness, tingling and burning pain in the feet and hands; frequent oral yeast infections; and an altered sense of taste.

Worthington's taste buds are now much less sensitive, she said, and when she cooks she has to be careful not to use much garlic, salt or pepper.

She uses a variety of medications to relieve her symptoms, including one that stimulates secretions throughout the body, special eye drops that treat both the dryness and inflammation, and regular eye drops throughout the day.

Now that she and her doctors know what they are dealing with, she is checked every three months by a rheumatologist for signs of lymphoma, every six months by a dentist and every year by an ophthalmologist.

[TECHNOLOGY]

Spicebird: Open source e-mail done right

While traditional desktop-based e-mail remains indispensable for most, Spicebird is a new alternative that's free, full-featured and worth checking out

BY JAY DOUGHERTY
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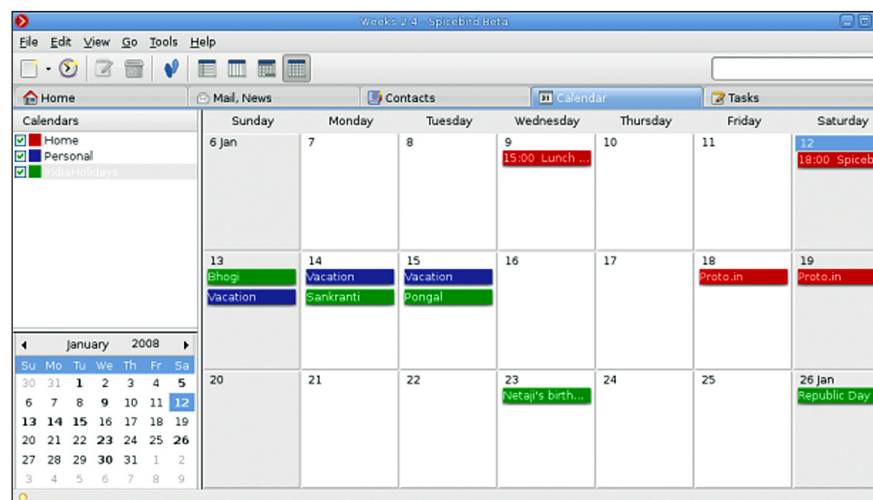
Web-based e-mail services may get most of the attention these days, but traditional desktop-based e-mail remains indispensable for most. That's in part because of history — people are still accustomed to downloading their e-mail into a traditional application — and in part because many have grown dependent upon the additional features that have come to be seen as essential to e-mail programs but are lacking in Web-based e-mail: contact management, calendaring, and more.

The trouble is that Microsoft's Outlook has come to dominate the e-mail application market, and the serious competitors have gradually fallen away. Outlook enjoys a near monopoly status — with prices to match. Mozilla Thunderbird has won the hearts of some as a viable alternative, but Thunderbird is essentially an inbox tool, lacking some of the essential functions found in Outlook. A new alternative, though, has emerged: Synovel Technologies' Spicebird is an open-source Outlook competitor, offering full-featured e-mail functions, a built-in news reader, contact management, calendaring, and task management. It's free, full-featured and worth a look.

TABBED INTERFACE

Spicebird's tabbed interface borrows from the tabbed layout of most browsers today — and will therefore be immediately familiar to those who have become accustomed to switching from one area of an application to another using tabs along the top of the content area.

Instead of switching from one Web page to another with tabs, however, Spicebird's tabs are used to move from the e-mail component to contacts, calendar, tasks, and the home page,



Spicebird's functionality and its look and feel can be enhanced beyond the basic package by downloading and installing plug-ins, extensions and themes.

which is entirely configurable, with items such as news from the Web, RSS feeds, world clocks, and calendar items all able to be displayed.

Keyboard mavens can even use the same keyboard shortcut — Ctrl-Tab — to move from one tab to another in Spicebird as they can from one tab to another in a Web browser. And keyboard lovers will be enthused, too, at how much of the functionality built in to Spicebird can be tapped without ever touching the mouse.

The interface in general is highly configurable. It can be loaded up with colorful icons or stripped of button bars, status bars, and side bars altogether to provide a no-nonsense workspace for sending and reading mail and working with daily schedules and contacts.

SETTING UP SPICEBIRD

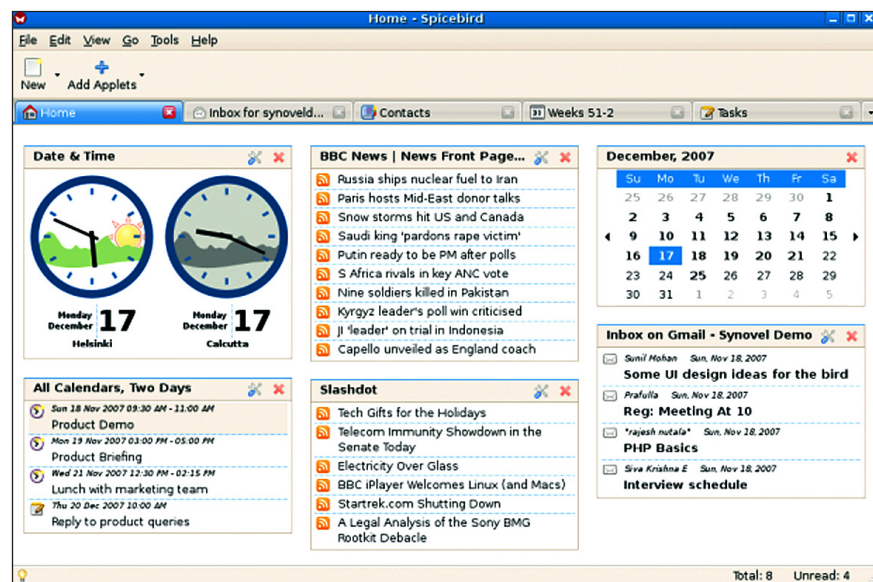
Spicebird is simple to set up, whether you want to use it as a replacement for your current e-mail program or on a trial basis to figure out whether it's worth the effort.

During the installation process, you're given the choice of whether to import your existing mail from the major e-mail programs in use today — Outlook, Outlook Express, Eudora, and even Gmail. The latter option is particularly interesting in that Spicebird gives you a way to access your Gmail in a conventional e-mail program with no configuration other than supplying your Gmail user name and password.

If you set up Spicebird to handle your Gmail, in fact, you'll get the best of both worlds: desktop-based access to your Gmail, including a taskbar pop-up that notifies you of new incoming Gmail, as well as continued access to Gmail through your Web browser. You don't have to worry about importing mail from your other e-mail programs right away, either. You can try out Spicebird and import e-mail and settings later.

FEATURES

A primary reason that people continue to turn to desktop e-mail programs like



Outlook is because of built-in contact management and calendaring abilities. Outlook, in essence, is as much a contact manager as an e-mail program, and here's where Spicebird takes direct aim at Outlook.

Spicebird has both a Contacts and a Calendar tab, and both offer features that will stand up well to those offered in Outlook. In Contacts, you can create address book entries on the fly, or you can import your existing contacts from Outlook, Eudora, or a text file. The same goes for the Calendar tab. Import your settings from Outlook, schedule appointments with others, and get a view of your schedule by the day, week, or month.

The e-mail part of Spicebird is full-featured and will be instantly familiar to Outlook users. The screen is organized in the same manner, with folders in a left-hand pane, message headers to the right, and the text of messages in a window below the headers. You can create folders for different types

of e-mail messages; a filter function, similar to Outlook's, allows you to route specific types of incoming messages to particular folders. An included spam filter works reasonably well.

While Spicebird offers discrete areas of the program for mail, contacts, calendaring, and tasks, these functions are, in fact, fairly tightly integrated, or at least aware of one another. For example, if you receive in e-mail message in which Spicebird detects an appointment or meeting, the program will provide a link that allows you to add the event to your calendar. Clicking the link will take you directly to your calendar tab.

Like Mozilla's Firefox browser, Spicebird's functionality and its look and feel can be enhanced beyond the basic package by downloading and installing plug-ins, extensions, and themes. Among the plug-ins included in the initial download are a Windows Media player and Acrobat reader; the single extension included in Spicebird is the instant messaging client. You can actually install

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other instant messaging clients, as well, including GTalk.

WHAT'S AHEAD

Synovel has some impressive plans for future functionality of Spicebird. Although the current version is still beta software — or pre 1.0 — Synovel plans to include tie-ins to blogging software even before the official 1.0 release. With this feature, you'll be able to post to your blog simply by sending an e-mail message, and any comments posted to your blog will show up in Spicebird as replies to your e-mail message. You'll also be able to store instant messaging sessions. The official 1.0 release is planned to have a Microsoft Exchange connector, as well, which should make Spicebird a viable replacement option for Outlook in business environments.

COMPATIBILITY AND AVAILABILITY

Currently Spicebird is compatible with Windows and Linux. The current version is Beta 0.4 but is quite stable, probably because several of the application's core functions are based upon technology that has been in the open source community for some time and is fully tested. Download Spicebird from www.spicebird.com/download.