SPECIAL ISSUE:
What You Should Know About
Oral Health & Spondylitis
ON POINT

The special issue of Spondylitis Plus that is in your hands was inspired by SAA members and friends who have expressed to us their frustrations associated with getting appropriate dental care due to mobility limitations as a result of spondylitis.

Most often, when we think of spondylitis, we think of the spine, the hips, the neck. However, as a systemic disease, we know that spondylitis directly affects many other areas of the body, as well. These include the mouth and teeth.

When we began to prepare this fall edition, our intent was to feature one article about spondylitis and dentistry. During the course of our initial research, we learned that the majority of people responding to our online poll reported that their dental professionals were not adequately versed in the special needs of a patient with neck or spinal fusion and concluded that education, both for the dental office and patient, is essential to ensuring optimal oral health for individuals living with spondylitis. As a result, we decided that the story was too big for a single article. Hence, this special edition.

I’d like to thank SAA Board Chair Craig Gimbel, DDS for contributing an in-depth paper that will be submitted for publication to a professional dentist organization; Chris Farrow-Noble, SAA member and contributing author; and Don Bunin, a longtime SAA supporter who shares a related story that describes the importance of having the right doctor on board and correct positioning in other surgical procedures.

I hope you will enjoy reading this special issue of Spondylitis Plus and I invite you to share your comments about it. As always, this publication is made possible entirely due to your generosity and its content is driven by your ongoing feedback. Thank you.

Please email me at laurie.savage@spondylitis.org with any comments or suggestions or just pick up the telephone and call. I would love to speak with you.

Best Regards,

Laurie M. Savage
Executive Director
From Denial to Acceptance

I had both knees, a shoulder and a hip replaced. I continued to have pain but no one would refer me to a rheumatologist. I even went to a back specialist who shrugged it off as just back pain.

But a year ago, I walked out of the doctor’s office stunned. I had been told I was HLA-B27 positive. Three weeks before, MRI and CT scans showed that I had inflammation in several joints, which blood tests confirmed. My rheumatologist knew immediately why I had pain and stiffness in my lower back and buttocks, why I had stiffness that was worse in the mornings and during the night, and spread up my spine.

Even though I have accepted that I have AS, at times it is hard to deal with, especially when I can no longer do things I did in the past, or when people tell me I look “fine”. My friends don’t believe me when I tell them I can’t do some things. I am somewhat angry now because I am on disability and must pace myself.

I do the best I can around people without trying to avoid them. My family is a big help and my cat Mitten is a loving companion. She always listens to all of my problems and tells me all is well. I still wake many times during the night. Now, I use a TNF blocker, anti-inflammatory drugs and pain medication to control the pain. I also found the SAA’s DVD Back in Action helps – even though I can’t do everything, but what I can do helps to keep me mobile. I take one day at a time.

I always tell people that I have good days, some are better days and some are not so good but I will try to manage as it comes, not only to accomplish everything that I want, but to put my health first. So thanks to my rheumatologist I am doing the best I can and hope to continue doing so.

Sincerely,
DIANE D.
Auburndale, WI

Editors Note: Diane, thank you for sharing your story. Philip Donlay’s story “From Denial to Support: One Writer’s Story” from the Summer 2010 issue of Spondylitis Plus appears to have struck a chord with many of our readers.

If you would like to share your story with us, please send your story to the address provided below.

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting or a concern you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to:
laurie.savage@spondylitis.org
Letters to the Editor/SAA
P.O. Box 5872
Sherman Oaks, CA 91413
Your visit to the dentist is important to the health of the rest of your body, not just your teeth and gums. It is important to be aware of the effects of spondylitis on the health of your mouth as well as the head and neck areas. At your initial dental appointment it is important to discuss your health history with your dental professional. For example, though ankylosing spondylitis primarily affects the axial spine, other axial parts of the body may be involved, as well, including the mouth. There are secondary effects of drug therapy that may cause dry mouth, infection or jaw bone degeneration. Secondary osteoporosis can even affect the jaw bone and the joint that allows movement of the mandible.
Correlations have been found between poor oral health and systemic disease. For example, there is a link between gum disease and cardiovascular disease and respiratory illness. The body’s impaired autoimmune defenses compromise the inflammatory response of oral infection. Be aware that spondyloarthritis is one possible factor that can lead to temporomandibular joint dysfunction, which includes clicking and impaired mouth opening.

**Seated in the Dental Chair**

Spondyloarthritis, being an axial and peripheral joint disease, has an effect on the posture and positioning of your head, neck and the rest of the body in the dental chair. Cervical spine stiffness or deformities may make it uncomfortable, or even painful, to sit in the dental chair for extended periods of time. If inflammation of the costovertebral joints of the chest wall occurs, limitation of chest expansion could result. Extraarticular manifestations include fibrosis of the lungs. This would force an individual to maintain respiration by labored diaphragmatic movement, making it more difficult to sit still. Cervical spine involvement may range from slight limitation of neck movement to complete fusion, usually in flexion or bending of the neck.

Fatigue is common among people with ankylosing spondylitis (AS). It is associated with inflammation and pain, in many cases. Your dentist should be made aware of these difficulties at the time of appointment scheduling. There may be a need for shorter appointments or making your dentist or hygienist aware that you must be accommodated with alternating periods of sitting in the dental chair, interrupted by position changing or standing in order to alleviate stiffness and pain. Just raise your hand. These requests can be accommodated very easily and will make your visit more comfortable.

Positioning of the head during a dental visit so that there will be proper support and minimal movement is very important. Many dental procedures require pressure or vibration. They range from the use of a dental drill or scaling instrument to that of an extraction surgical instrument that places pressure and subluxation movement on the jaw, head and neck areas.

For all oral surgical procedures, the preoperative workup should include evaluation of cervical bone erosion and ankylosis. In 21 percent of those with ankylosing spondylitis (AS), erosion of the odontoid process (projection from second vertebra of neck around which the first vertebra rotates) and transverse ligament (allows joint flexion) occur which could lead to anterior subluxation (rotation and displacement) of the cervical spine. This is associated with possible morbidity. In such cases, symptoms of occipital pain and tingling can occur due to degrees of spinal cord compression. This is more common in those patients with peripheral joint involvement.

Caution must also be taken to determine if vertebral fracture occurs at C5 - C6 or C6 - C7. Failure to detect fractures could lead to complications during surgery. Extremes of neck extension and flexion should be avoided during positioning of the head and oral cavity as they could lead to spinal cord compression.

This risk of subluxation is especially dangerous during general anesthesia procedures when neck movements are severely restricted and mouth opening is limited due to temporomandibular joint dysfunction. In these cases fiberoptic guided awake nasal intubation should be considered. Placement of a soft cervical collar is a visual reminder of an unstable spine, but does not provide any support in these instances.

**Osteoporosis**

Secondary osteoporosis and brittle bone due to spondyloarthritis have an effect on the mouth and surrounding joints. Even the jawbone holding the teeth in position can be affected. Osteoporosis causes osteoclastic bone remodeling and poor bone quality leading to loss of teeth, temporomandibular joint (TMJ) problems or even mandible fracture.

Depending on the degree of osteoporosis activity, rheumatologists and other physicians may prescribe a class of drug known as bisphosphonates, which prevent bone deterioration. These include Fosamax, Actonel, Boniva and Reclast. Even an oral dose of these drugs runs the remote risk of causing an exposed, “unhealing”, crumbling of the bone (osteonecrosis) at the surgical site following removal of a tooth or any bone recontouring procedure. It is extremely important that you advise your dental professional of your use of...
this drug regimen at the time of taking the medical history. A January 2009 article from the University of Southern California published in the Journal of the American Dental Association (JADA) estimates osteonecrosis risk from oral bisphosphonates at 4 percent. The American Dental Association Council on Scientific Affairs published an advisory statement in 2008 concluding the risk to be fewer than 10 percent of all patients taking orally administered bisphosphonate drugs.

It behooves one on bisphosphonates to practice meticulous home oral hygiene and visit their dentist for periodic exams and cleanings every six months or sooner.

Preserving your natural dentition promotes better nutrition. Most Americans do not consume the recommended levels of calcium. Supplementation with calcium and vitamin D is necessary to achieve and maintain peak bone mass, along with weight-bearing exercise to prevent osteoporosis. There is no scientific evidence in the literature to support discontinuing bisphosphonate therapy for dental treatment in order to improve treatment outcomes. Still, alternative dental treatment which does not include invasive oral surgery or extensive bone remodeling for implant placement may place you at less risk. Consult with your dentist and physicians to determine the best way to manage your treatment. This would include determination of bone mineral density (BMD), degree of risk of spine and hip fractures and duration of bisphosphonate therapy.

**Secondary Sjogren’s Syndrome**

Spondylitis may cause secondary Sjogren’s Syndrome, an autoimmune connective tissue disorder. It is characterized by inflammation of the exocrine glands (whose ducts ultimately open onto the external surfaces of the body) that leads to secretory hypofunction and dryness of the mucosal surfaces, most commonly of the eyes and mouth. A large majority with this disorder experience salivary gland dysfunction which can cause various oral symptoms and ultimately compromised dental health.

Sjogren’s Syndrome is the second most common autoimmune rheumatic disorder. The two forms combined (primary and secondary) have been estimated to effect up to 1 percent of the US population. The most frequent manifestation is dry mouth (xerostomia). Swollen parotid salivary glands may occur concurrently. In severe cases, ulceration and fungal infections of the mucosal lining of the mouth can occur. Dry mouth ultimately can cause severe tooth decay and gum disease. Saliva’s constant flow and natural buffering pH capacity helps to prevent decay and gum disease. Saliva contains calcium and phosphate ions that are responsible for remineralizing enamel. This protects the enamel surface from the destruction of acid forming bacteria in the mouth. A dry mouth creates an oral environment for gum disease. Difficulty with eating, swallowing and speaking may occur. Patients with secondary Sjogren’s Syndrome should see their dentists more often in order to prevent severe tooth...
decay or gum disease. A strict regimen of home oral hygiene is an excellent preventive measure. A large percentage of decay due to dry mouth is at the gum line. The enamel is thinner here and without salivary flow to flush out the gum sulcus which surrounds each tooth, decay and gum disease occur.

Salivary replacement therapy for dry-mouth symptoms is available either by a prescription or in the form of over-the-counter mouthwashes, toothpastes and sugar free lozenges and gum containing xylitol (ie: Biotene products). With the guidance of your dental professional, fluoride therapy (PreviDent 5000 prescription strength fluoride toothpaste) can protect the teeth against the ravages of decay. Oral lubricants such as vitamin E can be effective in soothing irritated tissue lining the mouth.

It should be noted that certain prescription medications can cause dry mouth and therefore exacerbate the condition. Alcohol has a drying effect and therefore should be avoided in beverages and in mouthwashes. Caffeine-containing drinks (coffee, tea, certain soft drinks) act as mild diuretics which promote fluid loss and could worsen dry mouth. Mouth breathers can also exacerbate the condition and therefore are encouraged to try to increase nasal breathing. If this is found to be difficult, an examination by an otolaryngology specialist is encouraged. The ambient air in many modern homes is found to be dry, especially in the winter, due to their heating systems. Therefore, the use of a humidifier, especially at night, is encouraged.

Dentists often have the opportunity to initially recognize secondary Sjogren’s Syndrome. With your co-diagnosis, early intervention can lead to appropriate preventive management, thereby minimizing or eliminating negative health consequences of tooth decay or gum disease leading to tooth loss.

**TNF Alpha Blockers**

The effects of drugs that mediate the immune system, such as the TNF alpha blockers (Enbrel, Humira, Remicade, Simponi), can increase the risk of serious infection compared to the general population, according to clinical studies. Accordingly, it is recommended that these drugs not be started in someone who has an active dental infection. It may be best to avoid these drugs with serious recurrent or chronic infections. TNF blockers should be temporarily discontinued when a serious dental infection develops or when antibiotics are required to treat an infection. With minor infections, at the discretion of your medical professional, TNF therapy may be continued because the benefits may outweigh the risks of temporarily stopping it. With elective surgery, such as surgical gum treatment or implant placement, there are no recommendations from the drug companies as to whether or not to temporarily stop treatment, as there are limited and conflicting data on the effect of TNF blockers on surgical outcome. Therefore, consult your dental professional.
and medical professionals as to their recommendations.

Sinus infection is sometimes encountered with TNF therapy. Any signs or symptoms should be discussed with your dentist. These may include headache, pressure in regions of the head or neck, mucous discharge or even tooth pain since the roots of upper teeth are in close approximation to the sinuses. Care must be taken since sinus drip may lead to secondary bronchitis or other respiratory problems. At any signs of fungal infection, therapy must be stopped immediately.

**Periodontal (Gum) Disease**

Proper oral hygiene is especially important for those with spondyloarthritis. A recent study (Periodontal disease in patients with ankylosing spondylitis; Pichon N et al; Ann Rheum Dis. 2010 Jan;69(1):34-8) shows that patients with AS have a significantly higher risk of periodontal (gum) disease. Autoimmune-mediated chronic inflammatory disorders such as rheumatoid arthritis (RA) and inflammatory bowel disease such as Crohn's Disease have also been found to be associated with periodontal disease. Although extensive epidemiologic evidence exists, the biological basis for this remains unclear.

Periodontal disease is a bacterial infection caused by pathogens in the plaque covering teeth. There exists emerging evidence that the oral pathogen porphymonas gingivalis may serve to break immune tolerance or amplify the autoimmune response resulting in inflammatory tissue destruction. Periodontal disease is the most common chronic inflammatory disease in humans. A network of innate and acquired immunity, inflammation, wound healing and bone tissue turnover play important roles in the ultimate outcome. Research suggests the increase of the pro inflammatory cytokine, tumor necrosis factor-alpha (TNF-alpha), is a factor. Research is pointing towards the oral cavity as a major battleground and source for other systemic diseases, including those that are immune-mediated.

A regimen of good home oral hygiene, professional cleanings of dental plaque and regular dental exams are important to potentially prevent the medical comorbidity of spondylitis. Close collaboration between rheumatologists, periodontists and dental hygienists is necessary for control.

**Cardiovascular Disease Risk**

Atherosclerosis is a major risk factor for cardiovascular disease. It has been demonstrated to have a strong inflammatory component. In the NHANES I and III population studies, there was found to be a strong positive association between periodontal (gum) disease and stroke. Some of the bacteria found in dental plaque enter the bloodstream during episodes of high bacteria. The result of infection with microorganisms interacting with the hosts' immune and inflammatory response contributes to high levels of inflammatory protein mediators called cytokines and C-reactive proteins (CRP).

Cytokines are released by blood cells called macrophages during their process of bacteria destruction. TNF alpha is an example of a cytokine. They are necessary to signal the immune cells which results in the inflammatory response. If the initial inflammatory response fails to resolve the infection, chronic inflammation occurs which is responsible for soft tissue and underlying bone destruction of gum disease (periodontitis).

During this chronic inflammatory phase, the liver releases C-reactive proteins. This has been shown to induce blood cell platelet aggregation typical of atheroma formation (“hardening of the arteries”) and thrombosis. Similarly, there exists a clinical relevance of CRP in axial involvement ankylosing spondylitis (AS) due to inflammation of the joints. CRP is an indicator of disease activity
and chronic inflammation. According to medical literature, those affected by spondyloarthritis have a multiplier risk of 1.5 for cardiovascular disease. The CRP risk factor for cardiovascular disease is increased when periodontitis and AS exist concurrently. Therefore, it is important to maintain proper oral hygiene under the direction of your dental professional.

**Temporomandibular Joint Dysfunction**

The temporomandibular joint (TMJ) is the bilateral joint of the lower jaw which enables initial rotational movement of the jaw followed by translational movement as the jaw opens widely. Pain and dysfunction of the TMJ is referred as temporomandibular joint dysfunction (TMD) which is commonly felt and heard as a clicking or popping. Inflammation and pain can occur when displacement of the fibrocartilagenous disc between joint capsule bone is displaced and compression of bone, arteries, veins and nerves occurs. Arthritis is a common condition affecting the TMJ. Degenerative and rheumatoid arthritis are the most frequently encountered. Cases of spondylitis related TMJ disorders have been reported. Some limited movement of these joints occur in 10% of those affected with AS. In longer standing AS, the incidence may increase to as much as 30-40%. Conservative and non invasive treatment of the temporomandibular joint are endorsed for initial care. The majority of those with TMD achieve good relief of symptoms with conservative treatment. Good oral hygiene and decay prevention is important as this prevents tooth loss. Tooth movement or loss due to gum disease or tooth decay can alter the bite (occlusion) leading to further degeneration of the joint components. Clenching of the teeth can further aggravate the condition, as well.

**Oral Health and Systemic Disease**

As an educated partner in your medical and dental care, making your dental professional fully aware of what spondyloarthritis is, and providing a complete medical and drug history, provides information which is important for your treatment and overall health. It is important to practice meticulous oral home care and continue to visit your dental professional just as you would your rheumatologist. Oral health is a constituent of systemic health. We are beginning to understand more and more the links between poor oral health and other diseases of the body. It must also be emphasized that spondylitis has the possibility to predispose patients to oral infection, and once infection is established, it can exacerbate other systemic problems.
Are you up for the Spondylitis Challenge?

What changes would you like to see on the spondylitis landscape this time next year?
New classes of medications? Increased access to care? A better understanding of the disease among primary care physicians? Earlier diagnosis? An end to the blank stares when you say the words “ankylosing spondylitis?” Validated prevalence numbers that will accelerate funding for medical research? Or even, -- a cure?

You probably answered, “All of the above.”

As a member of the spondylitis community, (and it really has become quite a dynamic community in recent years), you know of the tremendous advancements that have been realized in the last ten years -- even the last three years. We believe this is just a prelude of what’s to come.

We know that new classes of medications are currently being tested, due in large part to the breakthroughs in genetic research. SAA continues to lobby aggressively for increased access to care and we’re stepping up our efforts to educate primary care physicians about spondylitis and the importance of differentiating mechanical and inflammatory back pain. The recently launched media campaign will raise awareness among the general public while also driving people with unexplained back pain to take the validated screening test, thereby encouraging early diagnosis. We’re also working with the CDC’s NHANES project to generate definitive prevalence numbers.

And we never take our eyes off the prize – the cure.

Would you like to be part of making that day a reality?
Thanks entirely to contributions like yours, we’ve been able to focus on these key areas while still maintaining and growing our flagship programs such as the Spondylitis Educational Seminars throughout the country, our National Support Group Network, Peer/Mentor Program, Spondylitis Plus and www.spondylitis.org, to name just a few.

With your ongoing support, SAA can continue to pursue these and other program opportunities until the day we all envision becomes a reality.

Now you can double the impact of your donation dollars.
Your donations are always appreciated and always put to good use. But right now, thanks to a generous $50,000 Challenge Grant from the Jean & E. Floyd Kvamme Foundation, every contribution you make to SAA will be matched dollar for dollar. This challenge is for a limited time only, so please give today. All donations sent by October 31st, 2010 qualify for the challenge.

Whether you make a one-time donation, sign up for the SMART Program (Spondylitis Monthly Automatic Rewards Team), renew or upgrade your membership, your gift will be matched, if sent before October 31st.

Please give now to help ensure that we’ll have something incredible to celebrate one year from today.

Diann Peterson
Director of Membership
The majority of support we receive comes from the goodwill of individual donors like you who give generous yearly gifts to SAA throughout their lives. Some truly special individuals have gone a step further.

Two years ago, when we established the Quest Legacy Society, we began to receive notifications from our members that they had left planned gifts to SAA.

We would like to take this opportunity to acknowledge those individuals who have kindly remembered SAA in their estate plans. Members of the Quest Legacy Society play a principal role in ensuring that SAA can continue to fund medical research, provide educational program services and advocate on behalf of the spondylitis community.

But just as important, members of the Quest Legacy Society help to make certain that future generations affected by spondylitis are not alone -- without the resources needed to better manage the disease.

Our sincere thanks to the following members of the Quest Legacy Society.

Stephen and Grace Becker
Cecelia Bunch
Means Davis, Jr.
Richard and Deanna Day
Harvey R. Derscheid
Alan Fraser
David Fulle

Robert and Barbara Hasty
Jennifer Layden
Brian MacKenzie
Nancy Regan
Laurie M. Savage
Katherine Sprouse
Darren B. Wolpert

We invite you to become a member of the Quest Legacy Society by including SAA in your estate plans. While designating SAA as a beneficiary in your will or living trust is the simplest way to create a legacy gift to SAA without affecting your current financial situation, there are a variety of planned giving options that can be tailored to your individual financial and philanthropic goals. Thoughtful planning may not only reduce your tax burden but is also a way to leave a meaningful gift to future generations.

Of course, if you have already made a financial provision for SAA in your estate plans, please let us know so that we may honor you and show our appreciation by including you as a member of the Quest Legacy Society.

If you are interested in learning more about the Quest Legacy Society or how to leave a planned gift to SAA, please complete and mail the reply envelope enclosed or contact Susan Jones, Director of Development and Planned Giving at 800-777-8189, ext. 231 or susan.jones@spondylitis.org. To learn more about the Quest Legacy Society and estate planning, you can also go to SAA’s website at www.spondylitis.org/quest.

Remember: We respect your privacy. Your personal information will be kept strictly confidential.

“We make a living by what we get, but we make a life by what we give.” ~Winston Churchill


LIKE most other people with ankylosing spondylitis (AS), 83-year-old Don Bunin has had his ups and downs over the nearly six decades he has had the disease. The San Diego transplant has had his bad days and good (more of these than the other), but that didn’t stop him from having a successful career in chemical engineering and management or a post-retirement career as a drummer in local jazz bands. And, like many people his age, Bunin developed cataracts, a condition that occurs when the clear lens in the eye becomes cloudy over time, making it difficult to see clearly.

Cataracts removal is one of the most common surgical procedures in the United States, with more than 1.5 million operations performed in the U.S. each year. For individuals with AS, especially those with kyphosis (curvature of the upper spine), however, the procedure takes additional planning on the part of the surgeon and, as Bunin’s case shows, a whole lot of education on the part of the affected individual.

Like looking through a dirty window

A cataract is a clouding of the eyes’ normal clear lens; many people with cataracts describe it as akin to looking through a dirty window. This cloudy vision can make it more difficult to drive a car (especially at night), read or watch television. The lens is located behind the iris, the colored part of the eye. It focuses light on the retina at the back of the eye so that images appear clear. According to mayoclinic.com, cataracts “scatter the light as it passes through the lens, preventing a sharply defined image from reaching your retina. As a result, your vision becomes blurred.”

Unfortunately, many of us will develop cataracts. As we age, the lenses in our eyes become thicker and less transparent. Lens tissue often breaks down and clumps form, making the lenses cloudy.
together, causing the clouding associated with cataracts. As cataracts develop, the clouding can take over a greater portion of the lens, obscuring vision. Cataracts can occur in one or both eyes. In addition to age, conditions such as diabetes, high blood pressure, smoking and obesity can increase the risk of developing cataracts.

Most doctors recommend cataracts surgery when the condition begins to interfere with normal activities, such as reading or driving at night, as it did with Bunin. The most common form of surgery is called phacoemulsification, which uses a thin, ultrasound probe to dissolve the lens. The tiny pieces of the cataracts are then suctioned out of the eye through the same probe. Once the cataract is removed, an artificial lens, which helps your eye focus, is placed into the thin sac in which the cataract was located. The entire procedure takes about 30 minutes. More than 90 percent of cataract surgeries result in normal, restored vision.

**Positioned correctly . . . or not?**

Don Bunin’s cataracts began nearly 10 years ago, when he was in his early 70s. By the spring of 2009, the cataracts in his left eye got to the point where his doctor recommended surgery. “They slowly got worse over time,” he says, “to the point where night vision and glare from headlights were a real problem.”

The surgery was only partially successful, he says. The lens implantation went smoothly, but during his recovery period, there was inflammation in the eye (a not uncommon side effect of the surgery). The prednisone and NSAID (nonsteroidal anti-inflammatory drug) drops that he was given relieved some of the inflammation, but caused vision problems and elevated his blood pressure, Bunin says, because “my brain was straining to accommodate what was happening in my eye.” He also had large floaters, shadowy shapes that look like spots, thread-like strands, or squiggly lines in the field of vision. In addition, his ocular pressure (the pressure inside the eyeball) did not return to normal levels after the procedure, leaving him at risk for damage to the optic nerve and glaucoma.

While Bunin’s doctor had performed thousands of cataracts operations throughout his career, he admitted after Bunin’s surgery that it was “more difficult” than other cases because his head was not completely prone during the procedure, a necessity for someone like Bunin with AS and a kyphotic spine. “I can’t excuse the doctor for not having my head in the appropriate position,” says Bunin.

Thirteen months later, Bunin had the cataracts in his right eye removed, a procedure he says was “much different” than the first.

“My new doctor [the doctor who performed his first surgery had since retired] and I had a pact that my head would be flat during the procedure, and he assured me that it would be handled appropriately,” says Bunin.

The table in the operating room had legs that could be positioned hydraulically, from front to back, making positioning easier. Despite numerous people in the OR to assist with the procedure, Bunin says his surgeon took a hands-on approach to positioning him to ensure that it was done appropriately. In addition, the surgeon was aggressive with the use of anti-inflammatory drugs both before and after the surgery to decrease the likelihood of inflammation and to keep the ocular pressure down.

“My head was absolutely, completely flat [during the procedure],” says Bunin. “Both my surgery and my recovery went well. I had no floaters, my ocular pressure is normal, and everything has been fine since then.”

**A science, but not rocket science**

Positioning people with kyphosis can be difficult for cataract surgeons. While it sometimes takes ingenuity, other options, like the one used by Bunin’s ophthalmologist, are quite simple. Other options include placing the subject in a position in which the head is more vertical than usual, a more difficult approach for the surgeon. Another option uses a standard operating table and another small table. The patient lies down with his head on the small table, while the kyphotic portion of his back is fitted into the small space between the tables and supported by pillows or rolled blankets. Yet another places the subject in the Trendelenburg position (a standard position for abdominal and gynecologic surgeries) in which the feet are higher than the head. They are then supported with the use of straps similar to those used with a parachute. Most of these techniques use equipment that is readily available in the operating room and, most of all, they ensure that the head remains completely prone during the procedure.

Bunin’s take-home message to people with AS who require cataracts surgery is as simple as his second doctor’s approach to positioning: make it clear to your surgeon that your head needs to be completely prone before operating, and do not agree to the procedure until you are positively comfortable with your surgeon’s assurance.

“The OR for cataracts removal is like an airport terminal,” Bunin says. “The entire procedure takes about 20 to 30 minutes, and it’s one after another after another. More than anything else, patients need to make sure that their doctor knows that their head needs to be flat, even with minimal kyphosis. This is not rocket science.”
SAA members spoke up clearly about experiences and concerns around dental issues when 918 people completed at least some portion of the 25-question Dentistry and Spondylitis survey. More than 1,100 comments expanded the feedback to include narrative as well as statistical information.

This article examines the responses to the survey questions, organized in groups of related topics, and highlights significant statistics and comments. It also draws from interviews with two adults (one male, one female) with ankylosing spondylitis (AS) and one dentist familiar with treating special needs patients.

Identifying the Responders and Context

Nine hundred and five people, or 99% of respondents, had been diagnosed with a spondyloarthropathy. The vast majority -- 92% -- have been to a dentist since diagnosis, although many acknowledged challenges during dental visits.

Medical History

Fifty-eight percent of survey participants reported that their dental professional did not have an understanding of spondyloarthritis, even after taking a medical history, and 71% did not ask the patient what the disease entails. Shockingly, only 2% of dentists asked where they could obtain additional information about their patient’s condition.

The question about whether the dentist had a basic understanding of disease elicited the largest number of comments with 273 people adding clarifications. Responses were somewhat divided. Many clients had not mentioned their spondylitis or referred to it only as “arthritis” in an attempt to “keep it simple”. Several didn’t think it mattered. Thus, the dentists’ knowledge base may or may not have included an understanding of possible effects on the mouth and related issues with clients with spondylitis.

Others reported that when they mentioned spondylitis, their dentists seemed to be unaware or unconcerned by the potential side effects and interactions.

Many patients reported that their dentists did not take a medical history at all or that the history focused on medications and did not seek information about other issues that might affect the standard of care. Several dentists only became aware of their patient’s condition when they required antibiotics prior to dental treatment or were unable to recline in the dental chair or sit with existing head support.

Continuing Dental Care

Ninety-four percent reported that their family dentist remains comfortable providing dental treatment after learning of their medical condition. Of the participants who stated that their dentist no longer felt competent to continue their care, only 17% reported that they has been referred to another provider.

Pat, a 60-year-old female with AS, described the frustration of trying to find an accommodating dentist with her fused spine and inability to turn her neck. She believes some dentists’
refusal to treat her relates to possible fear of liability.

Dr. P., a dentist with 30 years in practice, explained his strong belief in “universal patient acceptance.” He considers this concept to be his first and foremost responsibility and has learned to accommodate all of his patients.

**Osteoporosis**

The majority of respondents (60%) were unaware of the risk of neck fracture to persons affected by spondyloarthritis. Almost all added comments that ranged from surprise to appreciation to distress at learning of the connection between dental procedures and these types of fractures. A few recalled experiencing multiple extractions and aborted dental procedures out of fear of neck fracture. Because of the spondylitis patients’ intolerance of longer dental procedures, they often opted for quicker procedures, such as extractions, rather than endure more complicated procedures that would otherwise have been available to them.

**Dry Mouth**

Approximately 37% reported that they are affected by dry mouth. Of these, 45% knew that dry mouth may be related to spondyloarthritis, and 54% knew that tooth decay may occur as a result. Less than 30% had been informed about special products that can help with this problem.

**Gum Disease**

Forty-three percent knew about the possible consequences of uncontrolled gum disease, and many others expressed gratitude for this new information. Some had heard about the coincidence of a higher C-Reactive Protein (CRP) during a flare-up but had not made the connection to a possible link to clogged arteries and heart disease. Eighty percent were informed by their dental professionals about ways to prevent gum disease.

**Temporomandibular Jaw Joint Dysfunction (TMD)**

Approximately 36% of survey participants suffer from temporomandibular jaw joint dysfunction (TMD), yet only 13% had a discussion with their dentist about the possible relation to spondyloarthritis joint deterioration.

**TNF Alpha Blocker Drugs**

Approximately 52% of those who participated in the survey were being treated with a TNF blocker. However, only 16% of those had a discussion with their dental professionals about the possible side effects of these medications. Only 10% of dental professionals discussed the risk of sinus infection associated with TNF alpha drugs.
Comfort in the Dental Chair

Nearly 72% did not notice any special precautions being taken during dental treatment to support the neck and head, and 213 commented on their experiences. Being able to sit comfortably in a dental chair and keeping one’s mouth open for extended periods of time were the most consistent concerns. Many people reported requesting extra pillows or towels to provide additional head, back and neck support.

Others did not ask for special accommodations but preferred to be treated just as any other clients.

The spinal columns of many spondylitis patients do not conform to the curvature of the contemporary dental chair. Pat, who was diagnosed with spondylitis 30 years ago, could not locate a dentist who would take her as a client. “I cannot lay back and/or put my head all the way back.” She found that dentists were no longer willing to treat her in a sitting position.

Other participants complained of long appointments without the opportunity to get up and stretch. Many spoke of the inability to open their mouths widely and noted some dentists’ lack of sensitivity to this physical limitation. Most who commented believed that it is the client’s responsibility to inform the dental professional of their special needs. A smaller number perceive speaking up for oneself as asking for special treatment. For this group, being treated “like everyone else” is important and desirable.

Dr. P. noted that he takes his cues directly from the client. He knows he must listen carefully to the patients’ explanations and requests and adjust the chair and positioning to their needs. He utilizes moveable head rests, small pillows for support, and always asks if the client is comfortable. He has also treated patients in their own wheelchairs and on gurneys.

Dr. P. considers appointments to be an ongoing dialogue about the patient’s comfort, ease of opening the mouth, fatigue, and need for breaks during treatment. He urges patients to keep him informed by saying, “I need your help to know what works best. Do me a favor and keep me informed.” Facial and body language are helpful clues as well but nothing is as effective as direct, verbal communication.

Bisphosphonate Medication for Osteoporosis

Approximately 11% of survey participants were taking bisphosphonate medication, and less than 25% of those were informed by their dentists about the possible consequences of the drugs. Alternative treatment plans were discussed in only 17% of the cases.

Summary and Next Steps

Analysis of the survey results reveals two strong conclusions: the need for continuing education about spondylitis to dentists and hygienists, as well as to persons with AS or one of its related diseases; and that patients who are vocal about their needs and limitations are more likely to have a satisfactory experience at the dentist’s office.

SAA is continuing to provide educational materials, including this special issue of Spondylitis Plus, to advance the effort of educating dentists and persons with spondylitis about the crucial links between spondylitis and dentistry. But we can’t do it alone. As a person living with a spondyloarthropathy, you are in a position to educate your dental health providers directly, in a one-on-one environment. In addition to providing important information to your dental professionals, speaking up about your own specific requirements, whether it be additional head or neck support, stretch breaks or alternative positioning while in the dental chair, will result in your being more comfortable and therefore, more likely to be consistent in seeking appropriate dental care.
SAA-Sponsored Educational Support Groups

If you’d like to find out more about support groups and for a complete list of groups and meeting dates, visit our website at: http://www.spondylitis.org/patient_resources/

You can also contact Elin Aslanyan here at SAA by calling 1-800-777-8189 ext. 222 or by email at elin.aslanyan@spondylitis.org for more information.

Recent Meeting Highlights:

Where: Hettinger/Bismarck, ND
When: Saturday, June 19
Rheumatologist Prashant Kaushik, MD spoke on the topic of the Medical Management of Spondylitis

Where: Spokane, WA
When: Saturday, August 14
Physical Therapist Bob Paul spoke on the topic of Physical Therapy for Spondylitis

Where: Houston, TX
When: Tuesday, August 10
Dr. Jaime Robledo from Advanced Interventional Pain Consultants spoke on the topic of Pain Management

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The Spondylitis Association of America is solely responsible for the content of this news magazine.

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Save The Dates! Upcoming Free Spondylitis Educational Seminars!

Portland, OR
Saturday, September 25, 2010

Atlanta, GA
Saturday, November 6, 2010

Email us at reservations@spondylitis.org or call Elin Aslanyan toll free at 1-800-777-8189 x222 for information. Or visit our events page at:
www.spondylitis.org/seminar.html

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S.M.A.R.T. is a safe, secure and convenient way to put more of your money to work advancing the spondylitis community’s shared mission. Just specify a monthly amount and SAA will automatically deduct the contribution from your credit card. At the end of the year, we’ll send you a summary of your giving and a tax receipt. Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership gift many times over.

To sign up for the S.M.A.R.T. Givers Program, go to www.spondylitis.org/smart or contact Helene Hart at 1-800-777-8189, ext. 229 or at hhart@spondylitis.org