WE ARE SEEKING REPLACEMENT FOR SOME OF OUR IPCSG TEAM
Serving in this team can be rewarding and is a way to pay it forward to the group. To offer your services and/or ask questions about functions, Contact any of the individuals at their listed phone number.

FUNCTIONS NEEDED:
1. President: IPCSG public relations, research and advice. Lyle LaRosh has performed for 18 years. 619-892-3888
2. Vice President: Support all team members, assist in monthly planning and speaker acquisition. currently vacant Gene Van Vleet has performed Functions 2, 4, 5 for 11 years. 619-890-8447.
3. Meeting facilitator: Monthly planning and speaker acquisition. George Johnson has performed for 8 years. 858-456-2492
4. Treasurer/Secretary: Handle banking, accounting, government reporting (see 2)
5. Hot Line: Communicate directly with newcomers and handle phone inquiries. (see 2)

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PCa are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Next Meeting
March 16, 2019
10:00AM to Noon
Meeting at Sanford-Burnham-Prebys Auditorium
10905 Road to the Cure, San Diego CA 92121
SEE MAP PAGE 10
PROSTATE CANCER
2 WORDS, NOT A SENTENCE

Additional Directors
Gene Van Vleet
George Johnson
John Tassi
Bill Manning

Honorary Directors
Dr. Dick Gilbert
Judge Robert Coates

George Johnson, Facilitator
Bill Manning, Videographer
John Tassi, Webmaster
Bill Bailey, Librarian
Jim Kilduff, Greeter
Chuck Grim, Meeting Set-up

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Editor: Stephen Pendergast

Video DVD’s
DVD’s of our meetings are available in our library for $10ea. Refer to the index available in the library. They can also be purchased through our website: http://ipcsg.org Click on the “Purchase DVDs” tab. The DVD of each meeting is available by the next meeting date.
Meeting Highlights “Member Panel” February 16, 2019
by Bill Lewis

Tim D’Andrea is 60 years old, and an engineer who went into technical sales. “My Journey.” He is currently in remission, after 31 sessions of proton therapy and 18 ongoing months of Lupron. His PSA is 0.24 and still dropping.

He was diagnosed in early 2018. MRI-guided biopsy found one core of Gleason 4+5, and a subsequent Ultrasound-guided biopsy found Gleason 3+3 and 4+3 in one side of the prostate.

During the previous two years, his PSA was in the range of 6 to 7. His FreePSA was 5%, suggesting a 49% chance of prostate cancer. The PSA4K test gave 77% odds of high-risk prostate cancer. His urologist pushed him to accept a random biopsy (not having the MRI-guided option there at Sharp Rees-Stealy), and had no knowledge of any support groups. He declined the biopsy, joined the IPCSG (“best thing I ever did”), and dove into research on the disease and his options.

He tried a naturopathic approach, including lifestyle (diet and exercise), supplements (apple cider vinegar, flaxseed oil, ginger root, baking soda/molasses, pomegranate extract, curcumin, Maitake, etc.) and 100-g doses of IV vitamin C. He also cut down on work-related stress – his company approved a four-day workweek for him. A second naturopath tried two antibiotics to rule out infection, checked with Color Doppler ultrasound (“normal” result), and gave many more (unpleasant) supplements. His PSA remained steady for about a year.

But then, his PSA rose to 9.5 in October 2017, so he put his IPCSG knowledge and network into high gear. The MRI guided biopsy mentioned above was done in early 2018, with only four cores. It was essentially painless, and gave hope for a focal treatment. But he had a second biopsy with 12 cores (and no anaesthesia – ouch!), which found more widespread cancer within the prostate, eliminating his hope of a focal treatment. In retrospect, he feels that more cores should have been taken in the MRI-guided session.

Dr. Scholz at Prostate Oncology Specialists recommended Radiation + ADT. Tim changed his medical network to UCSD, where Dr. Mundt recommended proton therapy, not X-rays (That’s a sign of a great doctor – he recommended a treatment other than his in-house capability!). So he went to California Protons, and was treated as noted above by Drs. Einck and Rossi. Last September, he was declared by Dr. Einck (also of UCSD) to be in remission, and told that he needs no biopsy now – just ongoing PSA testing.

Overall, he’s very pleased with his outcome, with IPCSG, and with his wife’s full participation (appointments, IPCSG meetings and research help). His regrets are having delayed the initial biopsy, and not having more tissue samples in the first biopsy.

Elliot Shev and his wife, Dr. Wendi Maurer (clinical psychologist in grief and loss), with “Our Prostate Cancer Journey.” Elliot is 71 and managing a facility in Tijuana for a large Japanese company. Current status: PSA = 1.7, feeling great, with all functions working fine.

After 5 years with his annual PSA hovering around 3.0, it rose to 4.7 by December 2017. After two weeks of antibiotics (to see if it was an infection), the PSA was 5.5, so they needed to make a decision. They chose immediate action, and went to see a urologist. This led to a biopsy (not pleasant!) and Gleason score of 4+3, with Stage = T2b (one side of prostate diseased). He was given a bone scan and a “high contrast abdominal MRI.”

They were referred to a surgeon and radiologist. They recorded every conversation, and had them
transcribed. They talked to family members (some are experts in medicine) and “everyone” they knew, despite this aggressive inquiring leading to occasional embarrassing moments (“What’s your PSA?”). Surprisingly, very many of them “had a story,” and they always made notes. They found that two friends had had HIFU (high intensity focused ultrasound) treatment.

HIFU is a “non-invasive” procedure which uses sound waves to image and destroy prostate cancers. Using real-time imaging, precise, focused ultrasound energy is delivered to the diseased cells of the prostate. Ideal candidates (per Stanford Healthcare) are men who hope to preserve continence and sexual function, currently have satisfactory sexual function, have cancer visible in MRI and confined to the prostate, and have a PSA below 20. Some references: “A Multicentre Study of 5-year Outcomes Following Focal Therapy in Treating Clinically Significant Nonmetastatic Prostate Cancer,” in europeanurology.com. FDA approval -- Medscape.com/viewarticle/853120. Doctors: Dr. Robert Pugach, Los Alamitos, CA, HIFUprostateservices.com and Dr. Steven Scionti, Sarasota, FL, sciontiprostatecenter.com. Much more info is available from Elliot by email on request (via the IPCSG).

Only the half of Elliot’s prostate which contained the tumors was treated, so he still has half of his prostate. Treatment took about 2.5 hours under total anesthesia, with 4 hours total at the clinic. His PSA dropped in 90 days from 5.5 to 1.7. He will be retested every 90 days for the first year, then get an MRI and a checkup with Dr. Scionti.

Lessons learned: Be your own advocate and case manager! Get an MRI prior to a biopsy, which should then be targeted. Talk to everyone. Don’t turn away loving support. Be patient with yourself and others. Doctors mean well, but they don’t know everything, and they are good salesmen for their specialty. Always, be your own advocate and case manager.

John Tassi is 63 years old, in satellite communications, and a 9-year survivor in remission. “What to Do if Your Prostate Cancer Doesn’t Return. “ In retrospect, his gradually rising PSA in his 40’s, reaching 3.5 at age 49, was an indication of prostate cancer, though his DRE (rectal exam) was still normal. The next year, he was incorrectly diagnosed with BPH (enlarged prostate). Two years later, in 2007, his PSA reached 19, still with a normal DRE. His doctor said, “You are too young for prostate cancer.” In December 2007, a biopsy revealed Gleason 3+3 on the right side and 3+4 on the left side. He chose Robotic-assisted Radical Prostatectomy, which was done in February 2008. Pathology of the removed prostate showed both sides had Gleason = 4+5, and that the margins were positive (Bad!). His PSA rose, doubling between August and October, so in December he started 37 sessions of IMRT (intensity modulated external radiation therapy), followed immediately in February 2009 with 5 sessions of Chemo using Taxotere, and in March 2009 with 12 months of ADT using Trelstar (equivalent to Lupron for testosterone suppression). Since then, his PSA has been undetectable!

More retrospective thoughts: He blindly accepted his urologist’s recommendation for surgery, which was “conveniently” available in two weeks. Although at first it seemed the cancer was gone, he was surprised to find it returned. He feels now that radiation should have promptly followed the surgery (common practice today, but not back then). He did become his own case manager, found the IPCSG, and went to a prostate cancer specialist (late 2008). Together with this doctor, his best course of action was mapped out: radiation, chemo, and ADT. He researched the best doctors for the subsequent treatments (three doctors for each, always asking “if you had my problem, who would you go to?”), and is alive and healthy today.

Recommendations: “Be your own case manager!” Seek out the best doctors, and don’t be afraid to FIRE YOUR DOCTOR – John has fired three. Request and keep copies of all your medical records.

(Continued on page 4)
Carry a condensed medical history, including a) Current medications, dosage, date started and doctor.  b) Discontinued medications c) Over-the-counter supplements (including list of ingredients) c) Any allergies.  d) List of surgeries and procedures, dates, where performed, and doctor.  e) List of your doctors with address and phone.  
  
Parting thoughts, regarding “yesterday” vs. today:  He doesn’t put off routine medical appointments and checkups.  He researches and understands his lab reports.  He asks the doctor questions.  He eats more moderately, and reduces consumption of sugar, salt and alcohol.  He uses a respirator around chemicals and in the attic.  He does still eat red meat and desserts.  He enjoys every day, not being hyper-focused on work.  He takes vacations.

Questions:
  
Why can’t we trust our doctor to give us good information – why do we need the IPCSG to be able to get it right?  It’s the specialization and fast-changing developments; the ordinary doctor can’t keep up.  Seeing an oncologist (rather than a urologist) is a help.

What did Elliot mean by “3D MRI”?  It’s the current advanced MRI, such as is available at Imaging Healthcare Specialists (more often referred to as mp-MRI, or 3T MRI, or nowadays, just “MRI.”)

More details are given in the video of these presentations, including the PowerPoint slides, which will be available for purchase via the website shortly before the next meeting, or at the March meeting on the 16th.

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**Lighter Side**

**FUTURE MEETINGS**

March 16, 2019  **Rana R. McKay, MD Medical Oncologist**

Rana R. McKay, MD, is a board-certified medical oncologist who specializes in treating people with genitourinary (urologic) cancers, including bladder cancer, kidney cancer, prostate cancer and testicular cancer.  Dr. McKay is part of the urologic cancer unit at UC San Diego Health’s Moores Cancer Center, where she works alongside a multidisciplinary team to provide patients with highly specialized care.  Dr. McKay will be discussing the Evolving Management of Patients with Metastatic Cancer & will highlight upcoming clinical trials of interest.

* For further Reading:  [https://spendergast.blogspot.com/2019/03/prostate-cancer-news-of-](https://spendergast.blogspot.com/2019/03/prostate-cancer-news-of-)*
Low-Dose Aspirin Doesn’t Prolong Survival in Prostate Cancer

By Steven Reinberg HealthDay Reporter

TUESDAY, March 5, 2019 (HealthDay News) -- Will an aspirin a day keep prostate cancer at bay? Not necessarily, according to new research.

Danish scientists say low-dose aspirin doesn’t seem to reduce a man’s risk of death from prostate cancer, but it may slow down the disease in some cases.

For patients with slow-growing, non-aggressive cancer, aspirin did appear to stop the cancer from progressing. A slight benefit was also seen among men who took aspirin for more than five years, the researchers found.

"Aspirin is widely used due to its established protection against cardiovascular diseases," said lead researcher Charlotte Skriver, from the Danish Cancer Society Research Center in Copenhagen. "Our re-
results, however, do not suggest an overall protective effect of low-dose aspirin used in the year after prostate cancer diagnosis on mortality from prostate cancer."

But growing evidence suggests aspirin might reduce the risk of developing and dying from colon and other cancers, Skriver said. It was thought that prostate cancer could be added to that list.

Researchers did see a small reduction in prostate cancer deaths among patients who took low-dose aspirin for an extended time, she said. More study is needed to confirm that finding.

Skriver said any potential benefit from low-dose aspirin needs to be weighed against the risk of gastrointestinal bleeding linked with its use.

For the study, her team collected data on more than 29,000 men, average age 70, who were diagnosed with prostate cancer between 2000 and 2011.

During nearly five years of follow-up, more than 7,600 men died of prostate cancer and more than 5,500 died from other causes, the study found.

The findings were published March 4 in the Annals of Internal Medicine.

Dr. Teemu Murtola, a professor of surgery at the University of Tampere in Finland, wrote an editorial that accompanied the study.

"Aspirin may have other benefits, but it is probably not helpful against prostate cancer," he said.

Murtola noted that aspirin was not associated in this large study with a lower risk of death from prostate cancer, despite promising previous laboratory studies.

Still, the risk was reduced among aspirin users in a subgroup of men with lowest-risk prostate cancer, he said.

"Future studies should aim to evaluate effects of very long-term, at least 10 years, of aspirin use on risk of prostate cancer death," Murtola said.

Dr. Anthony D'Amico, a professor of radiation oncology at Harvard Medical School in Boston, said the study doesn’t take into account the treatment patients received -- an important point, because treatment directly affects survival.

Variables such as surgery, radiation and hormone treatment are essential to tease out the real effect of aspirin on survival, he said.

It's not only the treatments themselves, but the combinations used and the duration that can make a difference, D'Amico said.

"This is not definitive, because there is too much lacking in terms of treatment specifics," he said. "It's interesting, but it doesn't mean you should take an aspirin."

More information
The American Cancer Society has more about prostate cancer.

SOURCES: Charlotte Skriver, M.Sc., Danish Cancer Society Research Center, Copenhagen; Teemu Murtola, M.D., Ph.D., professor, surgery, University of Tampere, Finland; Anthony D'Amico, M.D., Ph.D., professor, radiation oncology, Harvard Medical School, Boston; Annals of Internal Medicine, March 4, 2019

Last Updated: Mar 5, 2019

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Personalized Medicine Is Next Step in Castration-Resistant Prostate Cancer

Brandon Scalea
Raoul S. Concepcion, MD, FACS

The field of castration-resistant prostate cancer (CRPC) is moving forward with the development of several new treatment options, and the next steps for clinicians will be tailoring treatment strategies to each individual patient, said Raoul S. Concepcion, MD, FACS.

The phase III ARAMIS trial introduced a third androgen receptor inhibitor that may shake up the treatment paradigm for patients with nonmetastatic CRPC. In this study, the addition of darolutamide to androgen deprivation therapy (ADT) was found to significantly improve metastasis-free survival (MFS) versus ADT alone, with comparable tolerability to enzalutamide (Xtandi) and apalutamide (Erleada).

The findings, which were presented at the 2019 Genitourinary Cancers Symposium, showed the median MFS was 40.4 months for patients treated with darolutamide compared with 18.4 months in those who received ADT alone (HR, 0.41; 95% CI, 0.34-0.50; P <.0001). At a median follow-up of 17.9 months, the median time to pain progression also favored darolutamide at 40.3 months compared with 25.4 months with placebo, which translated to a 35% risk reduction (HR, 0.65; 95% CI, 0.53-0.79; P <.0001).

Although additional data will be critical in determining where darolutamide will fit into the nonmetastatic CRPC space, Concepcion, director of the Comprehensive Prostate Center, and clinical associate professor of urology, Vanderbilt University School of Medicine, said that cost could be the biggest deciding factor.

Beyond this approach, immunotherapy in the form of PD-1/L1 inhibitors could soon have a more significant role in the treatment of patients with metastatic disease, Concepcion predicts. As the space continues to move away from traditional approaches, the ability to interpret and utilize predictive biomarkers will become all the more important, as they will help inform which treatment will result in the greatest clinical benefit.

In an interview with OncLive, Concepcion, who is also the editor-in-chief of Urologists in Cancer Care, discussed the clinical implications of the findings from the ARAMIS trial and highlighted other therapies that are coming down the pike for the treatment of patients with CRPC.

OncLive: How has the results from the ARAMIS trial impacted the nonmetastatic CRPC landscape?

Concepcion: ARAMIS was a highly anticipated trial mostly because the drug itself, darolutamide, is structurally different than apalutamide and enzalutamide. In this trial, investigators were looking at patients with nonmetastatic CRPC, a very similar population to [those evaluated] in the SPARTAN and PROSPER trials. In other words, these patients had a diagnosis of prostate cancer, were on ADT, had testosterone levels in the castration range, and had rising prostate-specific antigen (PSA). They were imaged and

(Continued on page 8)
showed no evidence of metastatic disease by traditional imaging, which includes a bone scan and a computerized tomography scan. Enzalutamide and apalutamide are FDA approved for these patients. The inclusion criteria for these patients was to have a PSA doubling time <10 months, when in reality, this patient population has a doubling time less <3 months.

The theory of darolutamide being structurally different is that there may, in fact, be less toxicity relative to central nervous system (CNS) adverse events. What they reported out [at the 2019 Genitourinary Cancers Symposium] was what many people anticipated: the time to metastases was delayed versus placebo. But what would be the side effect profile? This [question] was specific to fatigue, because enzalutamide and apalutamide have a very significant fatigue factor somewhere in the order of 20% to 30%. What they reported at the symposium was that in the darolutamide arm, the incidence of fatigue was approximately 15%; in the placebo arm, it was 12%. Therefore, there is definitely a reduction in the incidence of fatigue. Again, the delay to MFS was pretty much similar to what we saw with enzalutamide and apalutamide in this nonmetastatic CRPC population.

These data are significant, and there will be more data coming out on this. [The questions of] how this is going to translate into practice and how we are going to use darolutamide versus the other 2 agents still need to be flushed out. Cost will be a big factor, and it will be interesting to see how long it will take for an approval.

**Where do you see darolutamide fitting in this treatment paradigm?**

This is going to be an interesting question. Now, we have potentially 3 agents that have been studied with positive trials in this setting. The challenge for clinicians is going to be: which drug do we use? For urologists in particular, our experience with enzalutamide going back to 2012 means that we are very comfortable with using it. Because apalutamide has recently been approved [by the FDA] and it is a very similar product, the urology world is getting used to this. With darolutamide, once investigators start looking at the side effect profile, what is going to be the willingness for the provider to use this drug? It will probably be related to how they view individual patients. If you have a patient who already has a lot of central nervous system toxicity and fatigue, darolutamide may be a more preferable option. However, like anything else, when you look at the primary endpoints, these drugs are very similar in their results. It may ultimately just come down to cost.

**What is the importance of evaluating quality of life (QoL) in clinical trials?**

We know there are so many agents that prolong survival. What many people do not realize is that in many of these patients with CRPC—especially if they are nonmetastatic—their ECOG performance status is 0; they are highly functional and active. These are not patients who are walking around in significant pain. The issue with some of these agents is that their side effect profiles may set these patients back. If therapy is going to slow down what patients are able to do on a daily basis, that becomes significant. I'm glad we are emphasizing QoL into the equation here. It is happening across the board with all of these targeted therapies, and it should become the standard in clinical trials moving forward.

**What does the future hold for immunotherapy in prostate cancer?**

Over the years, the utilization of ipilimumab (Yervoy) had minimal efficacy in CRPC. However, we know that mCRPC tumors are “cold” tumors—they are not that immunogenic. There are a lot of data now, especially in men with mCRPC who have moved through several lines of therapy, where we do see this mutational burden. There are [biomarkers] that come as a result of treatment pressure selection. The 2 that come to mind are microsatellite instability (MSI) and CDK12. If you take these 2 groups, a percentage of patients will actually respond to a PD-1/PD-L1 inhibitor. Therefore, there is going to be a place for our newer immunotherapies, but what [this will depend on] is the clinicians understanding which testing they need to order.
As we move from our traditional therapies, the ability to interpret these predictive markers becomes really important. Testing for MSI and CDK12 biallelic loss with anticipation that we will also see [FDA] approvals for PARP inhibitors—understanding where these factors lie, how to process the results, and make them actionable is crucial. The challenge is going to be utilizing these biomarkers and next-generation imaging.

**What are biggest challenges moving forward?**

If we start from initiation of disease, for newly diagnosed prostate cancer, the question is going to be, “How can we determine who most needs treatment? Who needs active surveillance?” Urologists are looking at that appropriately. We are even taking that one step further in asking who we need to biopsy. Just because a patient’s PSA is elevated doesn’t necessarily mean that they need to undergo a biopsy. We are [working on developing] a better understanding of how to utilize PSA in conjunction with some of this adjuvant testing—whether it be blood-based, urine-based, or now, imaging-based with magnetic resonance imaging.

With definitive therapy, some of the challenges are in patients with high-grade prostate cancer who we know are going to progress. Who are the patients who will benefit from adjuvant radiotherapy? We also know there are ongoing trials in patients who have been definitively treated and have a biochemical recurrence. We know these patients are at a higher risk of developing metastatic disease. The EMBARK trial is looking at these patients and giving them ADT alone, enzalutamide alone, or the 2 modalities combined; that will be a significant trial. Getting back to localized prostate cancer, we know that there is a trial looking at sipuleucel-T (Provenge) in patients who are candidates for active surveillance.

The point here is, for the practicing urologists, to really look at prostate cancer and try to isolate patients into these individual buckets. It does become a mastery of the clinical trials and the particular phenotype we are dealing with, as well as the drugs that are approved [by the FDA] or not. There is no doubt it is becoming complex. We are going to see more agents, and we can guess that immunotherapy will play a bigger role. We know some other mechanistic drugs will come to the table. For urologists, it used to be operating, putting the patient on ADT, then seeing what happens. Now, we have to critically look at these patients.


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**Novel Radiotherapy Shows Promise in Heavily Pretreated mCRPC**

Roxanne Nelson, RN, BSN  
February 14, 2019

A novel targeted radionuclide therapy has shown promising clinical activity and low toxicity in a group of heavily pretreated men with metastatic castration-resistant prostate cancer (mCRPC).

The novel product is Lutetium-177 (177Lu)-PSMA-617 (under development by Endocyte) is a radio-labeled small molecule that binds with high affinity to prostate specific membrane antigen (PSMA), enabling tumor-targeted delivery of beta-radiation. PSMA is over-expressed 100-1000 times in prostate cancers, and expression is further increased in metastatic and castration-resistant carcinomas.

The new results come from an updated report on 50 patients with PSMA-positive mCRPC who had progressed on standard therapies and were treated with the new product. The results show a median overall survival of 13.3 months, which is longer than the average 9-month survival time for men with this
NETW ORKING

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi is the webmaster of our website and welcomes any suggestions to make our website simple and easy to navigate. Check out the Personal Experiences page and send us your story. Go to: https://ipcsg.org/personal-experience

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

If you have the internet you can contribute easily by going to our website, http://ipcsg.org and clicking on “Donate”. Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042, San Diego CA 92142

Directions to Sanford-Burnham-Prebys Auditorium
10905 Road to the Cure, San Diego, CA 92121

Take I-5 (north or south) to the Genesee exit (west).
Follow Genesee up the hill, staying right.
Genesee rounds right onto North Torrey Pines Road.
Do not turn into the Sanford-Burnham-Prebys Medical Discovery Institute or Fishman Auditorium.
Turn right on Science Park Road. Watch for our sign here.
Turn Left on Torreyana Road. Watch for our sign here.
Turn Right on Road to the Cure (formerly Altman Row). Watch for our sign here.