So I’m going to talk about, less about the disease, I mean it was an amazing, inspiring overview of what’s being done support-wise out there and also for leukemia and I’m going to talk a little bit about some of the progress that we’ve made here with collaboration with my medical oncology colleagues, whatever you want to call them, adult oncology colleagues, some of them are here, I mean by letter. So I’m going to talk about AYA oncology in Pittsburgh and beyond.

So my disclosures are I do want to thank Sigmatov for generous support and educational grants just to pay for some of the expenses of this symposium. I don’t have anything to disclose, I don’t own stock in any pharmaceutical companies, and all my money goes to my wife, my children and now my dog.

So we talked, I mean there is going to be a little bit of overlap here even though I did have a chance to review Dr. Sander’s slides before so I was able to modify mine a little bit. But just to talk about you know an AYA oncology patient is defined as someone who is age 15 to 39. We are talking about age cutoffs at Children’s Hospitals, we didn’t have a defined age cutoff so I came up with one that the administration liked and it’s up to the age of 22 we can take care of all new oncology patients. And we have at least seen one young man who is now off therapy who is I think 21 and like 360 days and we accepted a transfer from another institution and he got appropriate ALL therapy and he’s now the manager of a Wal-Mart in Scranton, PA and he’s like 26 and doing great.
So where did that age range come from? Now this is a slide I did get from Dr. Blier as the Godfather, he does wear black all the time too, but he doesn’t talk like Marlon Brando in the Godfather, but this is a great slide that I’ve borrowed from him and used it over the years, is that in ‘75 through ’80 you can see there is a real peak. You can see that the AYA patients overall have some of the best survival rates with cancer, but over time in 5 year increments through advancement in both pediatric and older adult oncology regimens through the cooperative group’s work you can see that there has become – it went from really a peak to a valley to use Archie’s terms, I should say, and this was 2004 projected but it really has hung true. So we’ve really seen not a lot of improvement, things are not getting worse, things are just not improving as quickly as we wanted to, like Dr. Sender said.

So this was published and this is available online if you want, SEER data looking at the epidemiology of 15 to 29 year olds with cancer, and it really shows the tons of data to show that we are really not doing as well as we should be doing. And this is just a very simple bar graph, you can see this was presented to the President’s Cancer Panel that there really has been essentially a 30% unchanged deficit since 1975 for 5 year survival with young adults with cancer up to the age of 40. Now there have been advancements in some fields, I mean some areas of cancer, but others not so much. So it balances out to about breaking even.
So just to touch on the overall numbers, pediatric cancer is less than 1% of all cancer, meaning those under the age of 15. So what about AYA cancer? And looking at SEER data from ’96 to 2000 you can see when you expand it up to the age of 30 it’s another 1.8%, so it’s really not 1% of all cancer patients in the United States. When you go up to the age of 40 it’s another 6%, and if you go up to 44, if you dial up the age max there it goes another 10%, so it’s really a lot of patients out there, it’s not inconsequential. So the SEER data shows inferior overall survival for AYA oncology patients in the U.S., call for a PRG, and that’s Commissioner Gordon from the old Batman show if you didn’t know. And yes, get Batman while I have you on the line. And I prefer the old school cheesy overweight Batman. Got it, I’ll call for a PRG. Can I invite the Super Friends?

So what’s a PRG? This is actually where I first met Dr. Sender was at the PRG in 2006, the meeting in Denver. It’s the Progress Review Group, it identifies priorities for research and it’s a national initiative. The final product comes down, I’ll show you, you can access as a PDF online, you can read it, it’s a big file, it is amazingly well put together and I’ll touch base on it, you’ll see what the cover looks like of the end product of this conference. It really highlights key research priorities to galvanize the research community to undertake projects in specific areas of scientific need, in this case AYA oncology patients. And because of this influence on researchers and research programs at the NCI and across the nation, each PRG report really can be considered a national game plan.

So it was held in Denver, not Gotham City or Panam, if you are a fan of the Hunger Games Book, which is supposed to be Denver I think. In April of 2006 the first PRG focused, it was the first one
to focus on a population and not a disease. It was a collaboration between the NCI and the Live Strong Young Adult Alliance. It was the Armstrong Foundation, it was the first public/private partnership really to focus, to really put together a PRG and focus on this lofty goal. And there were people from the scientific medical and advocacy communities, there was even a geriatric oncologist there from Moffat Cancer Institute, I just remember meeting him, and he had a unique perspective on cancer in older adults and it gave us an insight into taking care of those that kind of fall through the cracks, to use a term that’s used a lot in this population.

So it was really to develop a national agenda for AYA oncology and the conclusions and recommendations were published a little later in 2006. And this, if you just you know do a search online for PRG and AYA oncology you’ll get this and it is a very comprehensive reference and it’s all based in science. So it discussed and really spelled out a lot of the factors that affect the stagnant or inferior AYA outcomes.

One of them is referral patterns. Just I used to have – I do have slides for each of these but I just wanted to touch on just one point on each of them and not show you a slide for each. But referral patterns are very important. As Dr. Sender alluded to, it depends upon what ER you show up, if you are a 19, 20 year old, what PCP you see as to where you will be treated, and that could have life altering implications. If you are sent to a doctor that’s not familiar with your disease but thinks they are familiar with your disease you’ll get inferior care and potentially inferior outcomes, meaning death. We know that up to the age of 15 90% of cancer patients are seen in pediatric tertiary care
centers but over that it goes way, way down into both community oncology facilities and also adult academic institutions. But a lot more are in the community.

Low rates of clinical trial enrollment, we’ll talk about that later. Dr. Sender alluded to that, but I’ll talk about what’s been published, the data we have here and changes that we’ve made. Compliance is an issue. Obviously if you have an emancipated young adult we don’t know if they are taking their medication as well as if they are at home and their parents are bugging the heck out of them to take their 6MP every night. Even that sometimes is hard when parents leave teenagers, young adults to their own devices. We can’t be sure of compliance, but we know that compliance leads to just a better success rate, particularly with ALL.

Delays in diagnosis and lack of insurance are also issues. We know that adolescents, young adults are the least insured population in the United States, that is hopefully going to change and I’ll just have a slide on that a little bit later. And also there can be delays in diagnosis. There was a study out of – what was cosponsored by AFLAC that Dr. Blier published that showed that if you had public insurance versus private insurance in a series they looked at with acute leukemias your diagnosis was more likely to be delayed. And also delay in diagnosis because we know that 20 year olds don’t get cancer, you know the football player who comes into the student care facility at the University of Pittsburgh with a lump under his arm couldn’t possibly have you know a non-Hodgkin’s Lymphoma, he just couldn’t. So that can lead to delays and there are thousands of stories of young adults with
cancer that talk about essentially being blown off for their complaints for weeks and weeks and weeks by a lot of different practitioners.

And then at the bottom we still don’t have a great understanding of the biology of AYA malignancies, we really don’t. That needs to be studied better. Doing tissue banks and having basic science researchers focus on this is really the key to it because why does a 21 year old do worse than a 19 year old? We don’t know. And out of this and out of the growth of the – of the Lance Armstrong Foundation came the LiveSTRONG Young Adult Alliance, which has had annual meetings where I got to meet several great colleagues, some of whom are here today. It’s the coming together of oncologists in different programs, different psychologists, psychiatrists, supporters. I’ve been hugged many times by Johnnie Imerman from I merman’s Angels as a result of going to these meetings. But we’ve really grown, we just had our 5th in last November.

It’s a coalition of different organizations I mentioned, really all focused on improving cancer survival for patients between the ages of 15 and 40 and it’s a very – the way Dr. Sender’s talk is reenergizing, this is a very energizing meeting to go to, it really inspires you, it gives you new ideas, survivors, advocates, relatives of survivors who started their own organizations, oncologists, psychologists, all people doing just amazing work and it gives you just a sense of community, everyone you know against a common problem.
This yearly meeting which has concluded now, I’m talking about the new incarnation of it as it moves forward, has really – has led to a lot of projects were we’ve looked at a lot of improving standards of care in the young adults which is easier said than done. Even talking about certification process for AYA programs, you know giving kind of a young adult alliance seal of approval for your oncology program if you provide the things that are mostly included in that 70K charter that Dr. Sender mentioned. So there are a lot of initiatives that were started, some of which are – have been completed but most of which are still works in progress.

So after 5 years it’s evolved. I didn’t come up with this name, it makes it sound more like a science fiction movie, but it’s called Critical Mass, the new, the Young Adult Alliance. I call it evolution, if you are Rick Santorum it’s intelligent design. But it has evolved and it is moving forward as a new entity and it’s going to have its first meeting in Atlanta in 2012 and I’m part of the planning committee for that, so that should be an exciting meeting. Other initiatives that have happened around the country, I thought my Santorum was going to get a few guffaws, but I guess not. You’ve got to know your audience.

I was going to say who is he?

Exactly. So the Children’s Oncology Group has through the AYA Committee that Dr. Sender and I were involved with at one time has embedded AYA oncology advocates in the committee of every disease, every disease committee I should say to ensure that there is AYA specific questions when
appropriate to be asked on COG protocols. I’m not sure this is going to make an impact, I know Dr. Sender is even more skeptical, but it’s something.

This is a new development, the NCCN which is an excellent resource focusing mostly on medical oncology but it’s an excellent public resource on evidence based treatment recommendations. They recently released after having several meetings evidence based guidelines for medical oncologists that treat young adults with Philadelphia chromosome negative ALL. And up to the age of 40 they recommend that those patients should be treated with pediatric high risk ALL regimen, you know pediatric inspired regimens like we talked about. So it’s nice that it’s finally been – that the NCCN is drinking the Cool-Aid to use a term, to use it.

Now Dr. Sender touched upon the 2010 Patient Protection Affordable Care Act. Now this is not going to completely solve the problems of the less insured young adult population, but having young adults on their parents’ health plans to the age of 26 will ensure that a lot of them will get better care whenever it comes to their cancer moving forward. Uninsured adults with preexisting conditions, i.e. cancer will be able to obtain healthcare coverage as well through this Act. So I think that that is – these are both big developments particularly in the world of AYA oncology.

And then the CDC is involved as well. They’ve recently organized a series of ongoing webinars, the second one was two afternoons ago and I was on it. I was privileged enough to be invited where experts in the AYA oncology field are focusing specifically on why patients are not being on clinical
trials, we know a lot of the reasons why but really looking at solutions to addressing these shortcomings.

Other resources, I know Dr. Sender talked about a lot of the great resources, these are a few more. Some of them have funny names, there is one for testicular cancer, it’s a virus called Single Jingles. There are a few that are, I mean there are some that have names that you can’t even put up on the screen in public display for the most part, but these are all great organizations that provide support for young adults with cancer and once they move on as a survivor.

Increasing awareness is a big part of getting the message out. Like the symposium today, these are all places where symposiums or lectures have gone on over the last 5 to 6 years. AYA programs are all popping up throughout the country, each addressing the problems that face – that we face taking care of these patients in their own way. Every hospital system is unique so it’s not a one size fits all. Given props to the people from Nationwide who drove from Columbus today even though Dr. Yeager I wish could make it as well, he’s kind of – one of their champions of AYA oncology. But we’ll let him know that he missed a really good time. So these are all places with programs that are popping up around the country.

Dr. Sender touched on the teenage cancer trust. They really do it right in the UK in a lot of ways besides having sperm banking covered by insurance, something we grapple with every time we have a post-pubescent young man who we want to bank sperm and money comes up as an issue. They
have inpatient oncology units up to the age of 26 all over the UK so these patients all get to hang out together and commiserate and while they are going through their therapy they form very lasting meaningful bonds and it helps the physicians and nurses take better care of them all under the same roof. And then there is a yearly conference that I try to get to, not yet been successful and then they have a whole series of concerts at the Royal Albert Hall to raise funds and Roger Daltry from the Who, who spoke on the earlier video is very actively involved in that.

So what about in the burg? It’s not like today unfortunately. So how I got involved with AYA it all started in the office with Dr. Ritchey, who I don’t think is here because he is rounding. But just to go back because I didn’t mention my introduction, I’ll throw in a little bit of personal story. I’ve been here about 4 ½ years working the – in different researcher’s labs, half the time, while taking care of patients half the time. And I wasn’t getting my NIH grants, I don’t think in my heart I really wanted to get the NIH grants but Dr. Ritchey pulled me in his office and said what are you going to do with your life, your career? Not you know – really which direction do you want to take now that it doesn’t look like you are cut out to be a lab researcher, your heart is not in it. What do you want to do? And I came up with a suggestion or two, and he as politely as Dr. Ritchey always – as polite as he always is, he shot it down very nicely my other ideas. And then he said how about starting a young adult oncology program here because that’s something that I floated out to a few people in the division a few years ago before you got here, and no one really was that interested. So initially it was just to look at sarcoma patients, but he said why not take this as your new direction? So I thought about 30 seconds and I said yeah, I can relate to the teenagers, I still act like a teenager, I have similar
tastes to them. I think this is—it was about probably a 30 second mulling over and I said I think that’s a really good idea, so it all started with an idea from Dr. Ritchey, so I give him credit for that.

So I got a business plan, I assembled a team, there was myself, Aimee Costello, I got her last name right now that she’s married in the audience, she’ll be speaking later about late effect. She’s our AYA Nurse Practitioner, also works with late effects as I mentioned, coordinates the care of a lot of our AYA oncology patients, becomes a point person, they text her with questions, she really becomes kind of a confidant as well as a care provider for them and she has really just done an amazing job in this role. Jake Cooper, who you’ll see talk later, has really taken a real liking to taking care of the adults and young adults with cancer, who is involved in a lot of our trips and he’s organized the Cure All Concert which we are continuing to plug which is on Saturday at 6:00 p.m. to raise funds for our AYA oncology programming for the stuff out of the hospital, the nonmedical support we do for our patients. And all of the Heme/Onc docs, I can’t name every single doctor or nurse and social worker and psychologist and PA and physical therapy that takes care of these patients with us. So it’s not just you know 3 of us or 2 of us or me, because that’s ridiculous, you can’t do all of that. It’s a massive team effort.

Over at the University of Pittsburgh Cancer Institute I have formed great collaboration with Dr. Mike Boyiadzis who hopefully will be here, if he’s not here now, who is the head of the Leukemia Program. Dr. Hussein Tawbi, who is the head of their Sarcoma Program, we’ve shared patients, we’ve consulted on patients going in both directions and patients on trials and I’ll show you some
data later, Ann Welsh who is here still I think as my mole, she is indispensable as helping us enroll patients over at the Hillman Cancer Center on our, on protocols or at least opening gates for discussion for myself and my colleagues to talk with our medical oncology colleagues to figure out what is best for each patient on a patient by patient basis. It’s not cookie cutter. A 19 year old who is in college and lives at home is probably best served in a pediatric hospital, whereas a 19 year old who is married and has a kid and has a job is probably best served in the medical/oncology facility. So you have to look at each patient individually. I’m still looking for more disease groups specific champions over at the UPCI and I hope in the future there will be more, more colleagues to form great collaboration with.

As far as physical space, people say you have an AY program, you know where is it? Well it’s more of a concept, it’s less of a space. We have our team lounges at both the inpatient and outpatient realm. We don’t have a divine space, this is in time this is something that’s been discussed as a possible change for the future. I’d love to have our own ward but there is space limiting even as big a hospital as we have. Our Heme/Onc Outpatient Clinic has 14 rooms, an infusions area and a teen lounge for the young adults to bid their time while they are getting infusions or waiting for a room to open up, our census can be tight.

We have an inpatient Heme/Onc BMT Unit that has 19 beds, it’s on the same floor thankfully as our clinic and our adolescent ward where more and more of our young adults and sometimes younger oncology patients are admitted for chemotherapy. We actually have a much cooler teen lounge than
anywhere else in the hospital, so I mean if I were a teen that’s where I would hang out if I was in the hospital. And at the adult Cancer Institute a few minutes away, 1.6 miles away, they are redesigning their Outpatient Clinic and there may be from some of the discussions I’ve had there may be some AYA specific space set aside for the young adults with cancer. So that’s something that I’m hopefully of for in the future.

Other members of the team that help you know take care of these patients day to day, you’ll hear from Carol May, Scott Maurer, Dr. Jakacki, we started our supportive care program years ago to really help take care of chronic pain and end of life care for all of our patients, but they provide I mean excellent care for our young adults who are not as expressive as our younger kids, I’ll just leave it at that. Some of them are just too expressive. And then Late Effects Clinic and Program that Dr. Tersak and Aimee run, you’ll hear more from them later.

Reproductive Health Issues, we’ve been working with Dr. Gina Sucato from adolescent medicine to help us with contraception questions, and her colleagues also help. We’ll hear from Dr. Serena Dovey later and Dr. Sanfillipo, I don’t know if he’ll be able to make it today, but I’ve collaborated with them over probably the last 6 years now. We’ve streamline sperm banking over those so that it’s only, it’s available 14 and up. It used to have a rule in the hospital charter it had to be 18 and up, which made no sense so one of the reproductive endocrinologists changed it to 14 and up, which makes sense. We have a consultation hotline for any fertility related questions for oncology and bone marrow transplant patients. We offer ovum harvesting and embryo storage, we’ll get more of
the specifics during the noontime lecture. And then we keep up on what each other is doing by we meet every 1 to 2 months in Magee Women’s Hospital in Oakland, it’s a group of pathologist researchers like Dr. Warwick who will be speaking later, reproductive endocrinologists, GYN/ONC doctors, myself, some other people from Children’s, some urologists have been known to show up and some medical oncologists have even made their way there, which is good. I want everybody there to be involved in these discussions. But we actually now have 3 IRB approved protocols focused on newer fertility preservation technologies, ovum harvesting and freezing, ovarian tissue cryopreservation, freezing ovarian tissue for both young women after puberty and girls before puberty. We’ve enrolled 2 patients thus far and testicular tissue cryopreservation which is unique and not really being done on the scale we are doing it anywhere in the country. We’ve enrolled 7 patients who have had testicular tissue frozen prior to getting toxic chemotherapy bone marrow transplant.

We have psychiatrists, psychologists here, we are soon to have an embedded AYA – not an AYA, an oncology psychologist and working with the behavioral health people both at Magee and here to have a jointly appointed AYA specific psychologist that would float between both the pediatric and medical oncology centers and still waiting to hear on the budgeting side of that, but that’s still a possibility. There are child life specialists who are indispensable you know for all kids of all ages, Mike Schulock who I saw the audience and Laura McCullough who we are sadly going to be missing when she takes a new job eastward are amazing and engaging and communicating with and making life more manageable for the young adults with cancer in the hospital here and on our trips. So
through them and through very generous fundraising from some people in the audience, Mass Media Room and other great fundraisers, Jennie’s Kids with Cancer we’ve been able to have more age appropriate movies, video games, computer games, paperbacks, magazines. We even take our patients on chaperoned outings, skiing once a year. We’ve been doing – I lost track but it’s probably at least 7 years. We used to go to the Poconos which was a real shlep, but now we do it at 7 Springs, which is about an hour, hour and a half away. Some people think we are masochistic for taking 25 15-20 year old cancer patients away without any other chaperones, just the 6 of us, but it is always an amazing experience, so I’ll just leave it at that. It’s great.

Now that’s wonderful but what about you know getting the – for getting them services outside the hospital, but what about closing the gap in clinical trial enrollment and survival? So first I went to look at, knowing this was a problem I went to look at the Children’s Hospital of Pittsburgh data. He’s now 12, he’s getting way too old, so that’s a cute picture of him when he was like 5. Clinical trial enrollment for new diagnoses, I looked at our database, Children’s Hospital of Pittsburgh from 2001 to 2006 we had 640 new oncology patients – maybe I should use this – 139 were aged 15 to 22, median age of almost 17 years. Overall 229 patients of all age groups were put on the clinical trial, 36%. So the pediatric oncologies we weren’t doing as well as we thought, we were in a lot of pediatric oncology talks, yeah, 60%, 70% on clinical trials. I looked at our data and we were full COG affiliate, yet we have as many trials as we can get open and we only 36% on clinical trials, 38% or slightly higher in the younger group, but if you look at the older group, 15 and up it was down to 27%, which was statistically significant. And then I wanted to know why. So I looked at
the reasons why and 69% of the patients not in clinical trials did not have a trial available, and that was even more striking in the older age group. So either they were closed or there just wasn’t one open at the time, and this has been since published.

So then what about clinical trial enrollment between the Children’s Hospital of Pittsburgh and the University of Pittsburgh Cancer Institute? This is kind of a busy slide but I wanted to look at the 15 to 22 year olds, over a 3 year period I got access to their largest database and I looked at patients in this age group and then we had 91 patients over this 3 year period, they had 121, that fit the bill. And clinical and trial enrollment 26% of these young adults were put on clinical trials where on the adult side only 4.1%. This is older data, I know that clinical trial enrollment has improved on the adult side, I don’t have that data yet, they are consolidating databases. So I’m sure that this overall is a little bit better. This is still better than the national average for most medical oncology facilities. Sometimes it’s as high as 10% but a lot of places they are lower than 4%.

The diagnoses don’t match up perfectly, so we do get more – we did get a little bit more of the leukemias, AML and ALL, but you can see even for those with ALL a third of them were put on trials, so you’ve got a Hodgkin’s, several, more than a quarter who were put on trials. Osteosarcoma only 1 out of 6 were put on trials, this was probably due to closure and transition between trials, 3 out of 4 brain tumor patients in this age group were put on trials, so you can see there are a lot of big goose eggs over here, and a lot of the patients put on trials were mostly through the Melanoma Program, which is a fantastic program at the UPCI.
So the first step you know to getting more patients is to raise awareness, so this is my weak attempt at growing a mustache from a (inaudible), my three kids did a lot better as you can see. This was to raise awareness for mostly men’s cancer issues, testicular cancer and prostate cancer. I may try it again next year because my 9 year old son actually was mad when I shaved, everybody else was very happy. So a way to increase AYA referrals and collaboration, I’ve given a lot of lectures both here and Grand Rounds, I’ve been asked to do another Grand Rounds in October by Dr. Perlmutter, out head of pediatrics. I’ve spoken at West Penn, UPCI at their Tumor Board, I met – I presented at the Community Oncology Business Meeting once, which is a story for another day, and Pediatric Grand Rounds at West Virginia University, I’ve spoken in the hot spots around Western PA, Uniontown, Washington, Frick Hospital, Dubois, passed a llama farm on the way, and this was my low point in overall attendance so today I’m definitely kicking the rear end of this session here.

I was invited to speak at the Pennsylvania Academy of Family Physicians Breakaway Education Session on young adults with cancer, particularly leukemia. And the only people that attended my session were 2 people, the person that invited me and then an elderly physician with hearing aids who passed out 5 minutes into my talk. That is not a lie. But as long as one – I don’t know if he got some of the message. That is a true story. But it was a nice trip to State College and they treated me to a nice lunch, so it wasn’t a total loss.
So I looked overall at the products of my collaboration with medical oncologists, you know, overall, because I keep a database of patients that have been discussed and referred, 80 total patients have been seen and discussed through the AYA program since its inception in 2006, averages to about 13 a year. These patients have not all been treated here, they’ve been treated at UPCI, AGH, West Penn and other area hospitals, there was a few international referrals. The diagnoses of which we’ve collaborated are really wide ranging.

And the collaboration, just to focus a bit on my work with my colleagues of UPCI, it’s been great and it hopefully will continue to grow. We really hope that it becomes more bidirectional, we have COG protocols as I mentioned open through the shared Pitt IRB so we’ve able to enroll patients and I’ll show you data over on the adult side on COG trials. Our CRAs here have worked very closely with the folks at the UPCI and have gone above and beyond the call of duty to open enroll patients over there, some of them are here today and I thank them for their efforts.

The AYA team over here, meaning myself and all of my colleagues really in the division are available for consultation all the time, and Dr. Boyiadzis has my cell phone number so he will call me whenever he wants, when he has a question and I’m fine with that. We have weekly Tumor Boards, I’ve been to a few Tumor Boards over on the adult side, I’m in discussions to see if we can have a joint AYA specific Tumor Board every month or two to focus on just these patients. The hard part is trying to find time and space for such a meeting when you already have so many other conferences between two oncology centers. And I tell everyone I talk to in the community we are
available all the time to accept patient transfers from outside and also the UPCI when appropriate for patients up to the age of 22. So it’s always worth having a discussion about each individual patient. So at our quarterly meetings which we have in the conference room of Dr. Davidson, the Head of the Cancer Center we discuss open protocols, new protocols that can be shared, discuss further ways to work together much like the Hands Across American Campaign of years back.

So this is the fruits of my collaboration so far. This is an album cover for people that are used to looking at music on an IPod, Crosby, Stills and Nash, So Far so. When I was thinking So Far I thought of this album cover and this album, 56 patients, this is the most up to date data, I looked at it a couple of days ago to make sure I had the right numbers. We are seen as a referral second opinion between Children’s and the UPCI, 26 of these patients are currently or were being treated or followed at Children’s and 30 at the UPCI, 6 are or were being treated on COG protocols at the UPCI including leukemic patients, patients with rhabdomyosarcoma and osteosarcoma.

So these patients have been seen by – all of the patients I’m talking about have been seen by all members of the AYA oncology team, a real wide variety of diagnoses, things we don’t normally see in pediatrics, adenocarcinoma of the colon, a young lady with Gardner’s Syndrome who I consulted one of the colon cancer experts on the adult side and he gave me excellence guidance and I’m following his guidelines even though as a teenager she – it’s best that she’s followed here and that’s working out well. PNET, MPNST, things that just roll of the tongue, quite rare malignancies but with collaboration I think these patients are getting the best care possible.
So has this improved clinical trial enrollment? Like I said we all hold hands and we talk and we sing kumbaya, but is it making a difference? So previously published data I mentioned over at the UPCI for a 3 year block, 4% of 15 to 22 year olds are put on clinical trials where 26% over on the Children’s side were enrolled. So then I decided to look from 2006 and beyond, so I looked at July, 2006 through June, 2010 to see if we were able to improve clinical trial enrollment in this population compared to our historical controls. So I looked at the 57 patients referred to our program during that time period from 9 different hospitals, the median age of the patients was 22. Of those at the Children’s Hospital of Pittsburgh there were ones that jointly discussed between us and our colleagues over on the medical oncology side, 23% were enrolled on clinical trials. Now that sounds low, but lower than we’ve had but this does not include patients that are 17 that show up with leukemia that we don’t have to discuss, we just treat, we get put on an appropriate clinical trial or offer them an appropriate clinical trial. So these are just patients that we have shared and discussed and collaborated on.

Of those that we’ve collaborated on at the University of Pittsburgh Cancer Institute 9 out of 27, or 33%, have been enrolled on clinical trials, both COG and Phase I trials over at the UPCI. So when I saw – I was just looking at the data one day a few years ago and I saw this trend, and I said we have a few patients here, and when I added them up I’m like oh you know that’s 25%, that’s 30%, that’s 33%, which is huge compared to historical controls. So then overall these numbers are small but it’s encouraging. And this was statistically significant.
And for those that like bar graphs a little bit better, I don’t know why this has a shadow in it, but this is the Children’s Hospital of Pittsburgh historical data versus this subset of patients which we collaborated on, and the UPCI 2003 to 2006 and then the patients that we shared. I don’t know the full denominator of all patients 15 to 22 that were seen over at the adult cancer center, mainly because the databases are not completely consolidated. At this point there is a lot of flux in that and also no, I don’t always have the ear of all of the medical oncologists because they have such a large group, but something that we are working on. But for the patients that we discuss more of them go on clinical trials so that’s a good start as far as I’m concerned.

So newer triumphs, I’ve officially after a lot of paperwork I’ve officially been given consulting privileges over at the adult cancer center, so I can go over there and instead of just meeting with families for 3 hours and discussing protocols I can do that and bill for my services, which is nice. The Leukemia Division headed by Dr. Boyiadzis of UPCI has agreed as an entire program to follow the guidelines, this was before the NCCN let out their recommendations but to treat all patients up the age of 40 as per the COG high risk protocol O232. And Dr. Boyiadzis and I are working on putting together that algorithm for all patients, for all I should say physicians to have access to.

So winding up a little bit, I’m going to finish up a little bit early because I talk fast and I’m not even caffeinated today. So I should have probably included some of those other slides, but the goal of the AYA Program is really to provide the best multidisciplinary care of 15 to 39 year olds in this tri-state
region in cooperation with adult oncology colleagues. And this is a very – being accomplished through forming a center of excellence, that’s kind of a kitschy catch-phrase but really working together with doctors on both sides of the adult and pediatric divide to focus on this population and their malignancies.

Research obviously, clinical research that I’m focusing on is to improve clinical trial enrollment, looking at new cancer therapies and through collaboration with Phase I consortium both in the pediatric world and the adult side and we’ve been able to do that. We have to study more and more which malignancies and which age subgroup are better treated on adult treatment approaches versus pediatric protocols because as Dr. Sender alluded to, it’s not a simple case of pediatric oncologists do a good job, adult oncologists don’t. That’s insulting to everybody when you say something like that. When it comes to ALL, on ALL protocols you can say pediatric oncologists and their protocols are better, but Hodgkin’s data is pretty equivalent in this age group using both pediatric and adult protocols and some non-Hodgkin’s lymphomas it’s pretty equivalent as well. So as a community we can learn from each other.

We also do have to assume that these patients have biologically different and unique cancers, and we really need good translational research to address this. Improving clinical trial enrollment is one way to improve survival but to really understand the cancers on a molecular level is really going to result hopefully in more leaps and bounds in survival rates. And it would be idea to have a unified research team to focus on that.
So conclusions is that this is a unique population of cancer patients, I hope you get that, if even one take home message hopefully you get that message by now after hearing Dr. Sender and myself speak. The reasons for the discrepancy in the survival improvements we haven’t seen is really multifactorial, it’s not a simple silver bullet solution, and that there are a lot of local and national initiatives to try to address this deficit. So one way as I mentioned over several slides to improve disease free survival is really to improve enrollment on cooperative national protocols, and take care of these patients as a multidisciplinary team containing both pediatric and adult, that’s why I bolded it, oncologists who really can fulfill the complex medical and psychosocial needs of these patients. And then we can close the survival gap that we’ve seen. And then we can celebrate it.