

THE APPALACHIAN AMERICAN INDIANS of WEST VIRGINIA



The Appalachian Indian Voice

June, 2015

Next Tribal Council Meeting – To be announced.

AAIWV Web Page:

<http://www.aaiwv-ani.org>

<p>Tribal Officers:</p> <p>Principal Chief – Wayne Appleton Rt. 1 Box 271 Lesage, WV 25537 hazmatwa@aol.com 304-762-2416</p> <p>Chief – Mel Charlton-Smith 501 Brown Ave Belington, WV 26250 Miska1967@yahoo.com 304-823-0255</p> <p>Tribal officer- Anthony Simms PO. Bx. 2109 Beckley, WV 25802 klandaghidrum@yahoo.com 304-860-5770</p> <p>Treasurer – Vacant</p>	<p>Secretary – Gail Murano RichardBeartracker@yahoo.com 304-787-3117</p> <p>Tribal Liaison-LaVerna Vickers elusivebfy@gmail.com 304-412-2578</p> <p>Tribal Council Lori Glover 304-864-0563 Dalphine Fields Teresa Johnston Pat Lowe 304-648-7455 William Mohler-304-772-5009 Richard Murano 304-787-3117 Bob Parkins Johnny Raven Mike Smith 304-823-0255 Phyllis Snead Tawanda Turner Zina Turner</p>	<p>Non-Native Council Position Vacant. Please Direct inquires to Wayne Appleton at 304-762-2416 or hazmatwa@aol.com</p> <p>Veteran Contact Danny Pauley k9dogs121600@gmail.com 304-561-7666</p> <p>Faith Keeper Mel Charlton-Smith Miska1967@aol.com 304-823-0255</p> <p>Newsletter Editor/ Subscriptions \$12 Yr. The Voice Vacant. Send inquires to: Rt. Box 271 Lesage, WV 25537 hazmatwa@aol.com</p>
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AAIWV UPCOMING EVENTS:

**** 2015 Events ****

September 28 – General Gathering – Covered Dish Picnic Social will be held at a park in the Charleston Area. Exact location and times will be announced in August via e-mail and AAIWV Web site. Please mark your calendars and plan accordingly. A Council meeting will occur at the Picnic if a quorum exists.

Look for future *Events & Updates* in future editions of the Voice and on Facebook or at www.aaiwv-ani.org

COUNCIL MEETING UPDATE:

Council met May 16, 2015 at the New River Unitarian Universalist Fellowship in Beckley. Internet was not available to allow on-line participation. Due to medical issues faced by some Council members either themselves or in their family, it was decided that it was unlikely that

we would have a quorum for Council over the next few months. As we are only required to meet quarterly, it was decided to recess Council until September. Council also decided that we would be unable to do the Powwow in Tucker County in August for the same reasons. Council discussed the outlook for the future of the Tribe. With approximately 6000 members, lack of

participation of the membership leaves a core few who do everything. This core has been working hard on behalf of all members. The comment was made that "If you are proud of the card, be involved, come to meetings. If not, why do you have the card?" It was decided to put this question to the membership via the newsletter, e-mail, Facebook, and on the Web Page along with a letter from the Principal Chief, Gray Owl. Council recessed until September.

~ **Gail Murano, Tribal Secretary**

PRAYER REQUESTS:

Creator,

We have become lost, ill, and burdened ...

I humbly pray for help. Help us to emerge from this pit of despair so we may help pull others from the pit.

Creator,

Our people have scattered by winds of storm..

I humbly pray for help. Help us find each other so we may unite once more.

Creator,

We are sick and out of balance...

I humbly pray for help. Help us heal ourselves so we may then help others to heal.

Creator,

I humbly Pray...Guide us towards your will.

~**Submitted Anon.**

CALL TO ACTION!!!:

AAIWV as a group has approximately 6000 members on our Rolls. Most of us are proud of our Native American heritage and ancestry. These are not the same as I know many folks who are proud of their "Indian" ancestry but are totally part of the "Dominant Culture". I also know folks who have a lesser "Blood quantum" who are culturally and spiritually immersed in the traditional Native American cultures. We as a group (tribe, organization, you can use whatever words you choose) are now facing a significant problem because of the aging of our Council and the lack of younger folks stepping up into positions of authority or committing to do work and carrying through on what they commit to do. Although there are some full members of Council who are younger, at age 68 I am one of the younger and healthier members of Council. We have several Council members with serious personal health issues that prevent their active participation in Council, cultural events such as powwows and

such. These elected Council members have had to resign due to their illness. In addition, a number of us have serious illnesses in our families. As an example, Chief Mel Charlton-Smith and Mike Two Wolves' son, Wes, desperately needs a kidney transplant and dealing with his medical issues is taking all of their time and energy. We had to make the decision to severely curtail our activities for the next several months because we just don't have the people we need who are both physically capable and who are willing to step up and make things happen. The "long and short of it" is that we must have other people step up and become more active. This is a critical need.

We had planned to have a powwow in late August in Tucker County. Because of the illnesses in our Council family and members we have to cancel this activity. We will also have fewer issues of The Voice sent out. In an average week I receive somewhere between 50-150 emails and phone calls. Rather than concentrate on writing for the Voice, I am going to try to catch up on my correspondence.

One valid reason for folks not to participate is for us to fail to contact them and let them know what is going on and how they can help. Therefore, I need folks to email me at hazmatwa@aol.com and confirm their home addresses and email addresses. The last time I sent out a group email nearly 150 names and email addresses had changed. We have also had a large number of folks who have moved and I am sure that the many of the US Mail addresses we have in the Rolls have changed because of the new 911 "Street Address" rules.

I am calling on each of you to examine yourselves and your souls. **We NEED help.** We need healthy young folks to pick up the reins and roles of leadership. We are in danger of losing all the cultural and historic parts of our Native American traditions in West Virginia. **We are NOT asking for money! We ARE asking you to become involved, to commit to help us carry forward our traditions and culture, AND to live up to those commitments.** There are many ways you may help. If you believe you can help, please contact me and help preserve our traditions and culture. Remember if we lose these things—our grandchildren will never know these important parts of our heritage. The question is simple; do the Tribe and your membership card mean something to you? If so, we need you to step up and be more active for we are at a critical juncture for our future. The choice is yours.

~**Chief Wayne Gray Owl**

KIDNEY TRANSPLANT HELP... A Plea from Mom:

Hi, I am mom, aka Mel Smith, aka Spirit Bear, lead singer of Mother Earth Beat and Chief of AAIWV. My husband, dad, is Mike Smith, aka Two Wolves, Council member of AAIWV. We are the parents of Wes, legal name Wade Edward Sparrowhawk Smith, and he is the reason we have taken a leave of absence until September, you see Wes is in end stage kidney failure and needs a transplant. Here is his story as found on his Kidney Transplant donation page at www.helpopelive.org

“Wade Edward Sparrowhawk Smith, known by family and friends as Wes, is a wonderful, happy little eight year old boy. Wes was born in April 2007 with the genetic disorder Williams Syndrome and without his right hand. At the age of three months, Wes had open heart surgery to enlarge his pulmonary arteries and repair a valve in his heart. Over the years Wes has struggled with various developmental delays and did not walk until just before his fourth birthday. Despite all of his challenges he has remained a shining light of joy to everyone who knows him. His upbeat personality, ready smile and infectious laugh have captivated all who know him.

In November of 2011, after a weekend visiting friends and horseback riding during Thanksgiving break, Wes was struck down by sudden onset kidney disease—Focal Segmented Glomerular Stenosis (FSGS), collapsing form. After seven months of treatments and despite repeated hospitalizations as well as outpatient treatments, Wes' kidneys have all but stopped functioning. Now, Wes needs a live-saving kidney transplant. Research has found that with FSGS there is a better chance of survival if a transplant can be done before needing to start dialysis. Wes must receive a transplant we hope that match can quickly be found!”

Well, Wes surpassed all expectations and managed to go 3.5 years before entering end stage kidney failure and needing to go on dialysis.

“UPDATE: April 2015 - Wes was hospitalized March 30th and has gone into complete kidney failure. After two surgeries, Wes was given a temporary hemodialysis port and a peritoneal dialysis port. While waiting for the peritoneal dialysis port to heal, he was started on hemodialysis. With the exception of one weekend break to home, Wes spent three weeks in the hospital transitioning from hemodialysis to peritoneal dialysis. He is now home receiving daily peritoneal dialysis treatments. Wade, our son Wes, cannot live without dialysis and without a kidney transplant, he may never have the

opportunity to live a normal life, or to even live.” Even with insurance, Wes' transplant and care is going to be, and has been, extremely expensive. He has undergone the transplant evaluation at the Children's Hospital in Pittsburgh. Along with the travel and relocation to be near the transplant center, there are also co-pays, deductibles, doctor visits, and the costly anti-rejection medications he will have to take for the rest of his life. All of this presents a challenge we cannot meet without your help.

In order to ease the financial burden, a fundraising campaign in Wes' honor has been established with HelpHOPELive (formerly NTAF), a nonprofit organization that has been assisting

the transplant community for nearly 30 years. All donations are tax deductible, are held by HelpHOPELive in the Mid-Atlantic Liver Transplant Fund, and are administered by HelpHOPELive for transplant-related expenses only. Please consider making a contribution.

If you are willing to help, we would be beyond thankful. We have managed to raise almost 2/3 of our goal of \$30,000. The funds go from everything to help cover the expenses of staying up at the transplant center for post-operative treatment and monitoring, will help cover live donor out of pocket expenses, medications, lost income due to absence from work for family caretakers (like mom and dad) and so much more. The fund has already helped Wes by covering the expenses of re-wiring his bedroom for his dialysis machine. You can go online to Wes's campaign page: <https://helpopelive.org/campaign/3555> or you can mail a check to:



Wes at an AAIWV tribal meeting, trying out the backhoe!

MAILING A CHECK?



Payable to: HelpHOPELive
Memo line: In Honor of Wade Smith
Mail to: HelpHOPELive
Two Radnor Corporate Center
100 Matsonford Road
Suite 100
Radnor, PA 19087

Thank you for your generosity and support.

Sincerely,

Mel Charlton-Smith, Michael Smith & of course WES!

~Mel Charlton-Smith, AAIWV Chief

MORE ON WES & KIDNEY TRANSPLANT...:

As I was writing the previous post Pittsburgh Children's Hospital called about Wes's final evaluations. We have had one person volunteer for testing, so they have moved up Wes's final cardio evaluation for transplant to June 10th. If this person is a match there could be a transplant before the end of summer! It is SO VERY IMPORTANT for us to increase Wes's transplant fund!

I am including part of a post that I put upon Facebook shortly after we got our first call from Pittsburgh Children's hospital. So, without further ado, the May 18th, 2015 FB post excerpt:

"GUESS WHAT EVERYBODY? Pittsburgh Children's Hospital called, we have an appointment for next Wednesday [May 27th] for final evaluations! However, they are now accepting names for live-donor matches for Wes. [YES, they are still accepting names for volunteers as it is seldom that the first person tested is a match]

For those of you who have expressed a willingness to see if you are a match for Wes, you need to do the following:

Call: 1-877-640-6746 OR 1-412-647-5489

*Tell them who you are, that you are interested in live donor kidney donation for WADE SMITH (use his legal name, not nickname), and give his Birthdate **April 24, 2007**. They may have other questions for you. My husband and I have both offered, and will be tested when we have our appointment, however, it is unlikely that we will even be allowed to donate because of our personal health issues.*

So please, if you have mentioned at any time that you would be willing to donate, please call THE NUMBER ABOVE not me. They will work out arrangements for you to be tested.

Then, from a blog I wrote about this, that included the donor information I thought it would be best to share it once, rather than repeat myself over and over. It must be the teacher in me! Anyway, excerpts from the blog:

"I had friends IMMEDIATELY calling...like within minutes of my announcement only for them (and of course us) to be disappointed because they had a health issue that disqualified them. I LOVE YOU SO MUCH! I don't care that you were disqualified... YOU CALLED....you were ready to fly out here and be tested. OK, I cried. Not because you were disqualified but because you are such a loving, giving wonderful person you were ready to drop everything and get tested.

Anyway to help all of you out there who are thinking of calling...go ahead and call, but if you want to see what THEIR qualifications (or I should say automatic disqualifications) are, then go here: <http://www.upmc.com/Services/transplant/abdominal-transplants/kidney-pancreas/living-donation-kidney-transplant-program/Pages/who-can-donate.aspx>

OK, so now you have all the pertinent info. What a roller coaster ride this is! They are trying to get the transplant team together for a final evaluation next week! Then she asked "do you have a donor?" Well of course my husband and I immediately said we wanted to be tested, but unfortunately Mike is automatically disqualified by heart attacks, a stroke, and cancer 13 years ago. I _may_ qualify, we'll see. Believe me if they say "you're a match but you need to lose 50 lbs"...welp...guess I'll be losing weight!!! I need to anyway, but what a motivator that would be!!! I can't imagine what we'll do if I am not a match for live donation. Of course he will be listed as well for all types of donation, but a live donation is so much better in terms of health of kidney, chances of the kidney surviving, even a better chance at finding a match if there are many donors to choose from. There is also more flexibility because it can be scheduled to work in the donor's timeline. No having surgery 3 days before your sisters wedding and missing it! You can plan it afterwards. Well you get the idea. And Wes's kidney transplant campaign fund with HelpHOPELive.org will help cover the donor's expenses. I read that the donor's expenses can range from \$5,000 to \$20,000 depending (on what? I dunno, but that was a national average). I am hopeful, I am fearful, I am ecstatic, I am overwhelmed. It's too early to get my hopes up, but I can't help it. Just hanging in there! I feel like I should be shouting from rooftops, taking an add out in the paper and calling the local TV and radio stations.

Believe me though...I am praying! Praying hard, and THANKING Creator for the great gift he has given us with Wes!

Needless to say we are overwhelmed. This is why my husband and I have not been able to be active the last several months for AAIWIV. WE LOVE YOU! We love AAIWV! However, I hope you understand when I say that my son must come first!

*Sincerely,
Mel Charlton-Smith*

~ Mel Charlton-Smith, AAIWV Chief