The Phoenix Metropolitan Area

As a professional, I encourage everyone including family members of HD Folks to use words such as "My loved one is a threat to him/herself and/or the family" when the authorities are called in. This does not guarantee action but if this is repeated over and over, it can help to move things along FASTER. Please insist using the phrase and in addition, use it in any and all reports. Often a paper trail will help you and your loved one at a later time.

ASU Speech and Hearing Clinics- The on-campus speech and hearing clinics provide high quality professional services to the public and those that have limited insurance coverage. To schedule an appointment, please call 480-965-2373 or send a message using the link <a href="https://chs.asu.edu/shs/contact?email=shsclinic@">https://chs.asu.edu/shs/contact?email=shsclinic@</a> asu.edu ASU Tempe, Coor Hall 2nd and 3rd floors Reserved parking is available near the ASU Tempe Clinic

Anonymous Testing: Tucson offers a self-pay option to patients who are interested in pursuing genetic testing. Patients would meet with the neurologist, psychologist, and genetic counselor in one day and have a follow up appt in 4weeks. Where they receive the test results. Pre-symptomatic patients results are not entered into the medical record and they are giving a benign diagnosis in the medical record.

Something to consider of utmost importance of testing being received through qualified genetic counseling programs that follow the HDSA and Inherited Disease

#### **Prenatal Genetic Counselor**

facility.

Dignity Health, Fetal Disease Center of Chandler Dr. Karina Seidl

<u>DKarina.Seidl@dignityhealth.org</u>
(480) 728-2222

## Foundation's genetic testing guidelines Juvenile Onset Huntington Disease (JHD)

Michael Kruer, MD
Director, Center for Pediatric Movement Disorders
Co-director, Neurogenetics Program
Phoenix Children's Hospital
mkruer@phoenixchildrens.com

#### **Genetic Counselor**

Dr. Christina Laukaitis, *MD*Applied Genetics and Genomic Medicine, University of Arizona, *Tucson*, *AZ*520-465-8796
Last name is pronounced like "bronchitis"

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602-933-0970	cmlaukai@email.arizona.edu
MEDICALSERVICES – PSYCHIATRY	MEDICAL SERVICES – Neurology
Paul Boulware, MD	Arshia Sadreddin, MD
Arizona Neurological Institute	Barrow Neurology Clinics
10474 W. Thunderbird Blvd., Suite 200	240 W. Thomas Rd., Suite 301
Sun City, AZ 85351	Phoenix, AZ 85013
(623) 972-3800	(602) 406-4261
Paul Butzine, MD	John Caviness, MD
14506 W. Granite Valley Drive	Mayo Clinic – Scottsdale
Suite 108	Dept. of Neurology, Movement Disorders Div.
Sun City West, AZ 85375	13400 E. Shea Blvd.
(623) 214-1141	Scottsdale, AZ 85359
	(480) 301-6328
Claire Damecour, MD	Holly Shill, MD, G
13624 W. Camino Del Sol	Barrow Neurological Institute
Suite 150	(602) 406-6262
Sun City West, AZ 85374	
(623) 584-9694	

HD Research
Barrow Neurological Institute – Dignity Health
Movement Disorders Group
Recruitment for HD study
(602) 406-4206 and ask for Edie Simpson, RN or
Mary Dunn, RN
Genetic Testing
HD testing for only \$150
Lab accepts outside samples as well, so patients
wouldn't actually need to travel. You can simply order
the test through our institution. Amanda Miller, LMSW
HDSA Center of Excellence
500 Newton Rd 1-308 MEB
Iowa City, IA 52242
P319-335-6640
F319-353-4438
or Shawna Shawna-feely@uiowa.edu
To order:
Online Ordering:
www.healthcare.uiowa.edu/path handbook/rhandbook/
test1078.html
To be completed by the patient and ordering provider.
The blood can be drawn anywhere, at a draw station or lab,
as long as it is accompanied by forms. Payment can be
done via credit card and/or check.
If you are going through insurance that would have to be worked out by the third party.

I to be ordered from
/clinical-dna-testing/search-
Genetics – Pediatric
MGH,
h Charles River Plaza,

	185 Cambridge Street
	Boston, MA 02144
	BOSTOII, IVIA 02144
	(617) 726-5721  www.dnalab.org  Fee Schedule: 3 weeks Sizing \$262.50 7-10 Business Days Prenatal \$850.00 4 weeks HD Prenatal Linkage \$1,350.00
Behavior Health/Therapy Services	Holly Shill, MD
Mental Health Association of Arizona	Barrow Neurological Institute
6411 E. Thomas Ave.,	350 W Thomas Rd,
Scottsdale, AZ 85251	Phoenix, AZ 8501
(480) 994-4407	(602) 406-6262
www.mhaarizona.org	(332) 133 3232
www.iiiiiaaii20iia.org	

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Satinder Purewal MD 6677 W. Thunderbird Rd., Bldg. I-164 Glendale, AZ 85308 (623) 878-2100	Mayo Clinic 13400 E. Shea Blvd., Scottsdale, AZ 85259 Catherine Hunt-Brendish, MS, CGC Brook McGloughen, MS (480) 301-4585
Arrowhead Behavior Health 9865 W. Bell Rd. Sun City, AZ 85351 (623) 876-1246 www.arrowheadbehavioral.com	Placement Services Good Hands Placement Agency – Always Free Assisted Living search and referrals throughout Maricopa County (623) 444-7702 15411 W. Waddell Rd., Suite 102 Surprise, AZ 85379 www.goodhandsaz.com
Sharon Bell, PsyD 8190 W. Deer Valley Rd., Suite 297 Peoria, AZ 85382 (623) 398-4814 www.sharonbell.com	Care Patrol Assisted Living Search/Referrals (623) 398-0501 (480) 626-2450 www.carepatrol.com
Non life Threating "Crisis Team" Mercy Maricopa 1-800-631-1314 We encourage everyone including family members of HD Folks to use words such as "My loved one is a threat to him/herself and/or the family" when the authorities are called in. This does not guarantee	Jackson White, Esq. Contact Daniel Nunez (480) 422-0979 Email: dnunez@jacksonwhitelaw.com www.arizonaseniorlaw.com Caldwell & Ober Law Firm 1940 E Camelback Rd # 150, Phoenix, AZ 85016

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action but if this is repeated over and over, it can help to move things along FASTER. Please insist using the phrase and in addition, use it in any and all reports. Often a paper trail will help you and your loved one at a later time.	Phone: (602) 277-1745  http://oberpekas.com/  * Social Security Disability (DIB)  * Supplemental Security Income (SSI)  * Appeal
Working You're your Insurance Company http://www.hdfreewithpgd.com/Page2.html	Stephanie Lake, Esq. Social Security Attorney 3737 N 7th St # 100, Phoenix, AZ 85014 (602) 200-9090 Email: frontdesk@stephanielake  http://stephanielake.com/contact Ober & Pekas Social Security Attorneys 030 North 3rd St., Suite 1230 Phoenix, Arizona 85012 602.899.0867 http://oberpekas.com
	Financial Services  Elizabeth Crosby, LCSW, LPFP: P:480.292.9068 icmfs@yahoo.com www.integratedfiduciary.com  Jeff Young, Senior Vice President

	First Financial Equity Corp. 1773 N. Scottsdale, Suite D-120 Scottsdale, AZ 85253 480-778-2041 direct   480.998.2883 fax   800.687.3800  [http://www.jeffyoungffec.com%20]www.jeffyoungffec.com jcyoung@ffec.com  Speros Financial 1475 N. Dromedary Rd. Phoenix, AZ 85018 602-531-5141
Michael Cofield PhD Banner Arizona Medical Clinic 13760 N. 93 <sup>rd</sup> Ave., Suite 104	Prenatal Exclusion Testing  Prenatal Exclusion testing was recently read about through this article <a href="http://en.hdbuzz.net/036">http://en.hdbuzz.net/036</a> The HDSA
Peoria, AZ 84381	headquarters explained that in the 80s and 90s this was
(623) 876-8438	done however it was phased out when Non-Disclosing PGD
	was introduced. The problem sometimes that on the
	average a Non-Disclosing PGD cost \$20,000. Check with your insurance and see if your insurance can cover any expenses.

Touchstone Behavioral Health	Life Insurance
(623) 930-8705	www.protective.com
www.touchstoneh.org	Protective Life
	Protective Life Corporation provides financial security
	through insurance. Is known not to ask about HD on their
	life insurance application
Behavior Health/Therapy Services	Social Services - programs aimed at financial, emotional,
Michael Cofield, PhD	and educational support
Banner Arizona Medical Clinic	Arizona's Caregiver Resource Line sponsored by Arizona
13760 N. 93 <sup>rd</sup> Ave., Suite 105	Caregiver Coalition
Peoria, AZ 85381	Toll free – (888) 737-7494
(623) 624-2450	www.AZCaregiver.org
	Telephone support for information and resources in your
	community including Respite Voucher applications for
	respite support for family caregivers
Rehabilitation Services – Outpatient	Arizona's Respite Locator sponsored by Arizona Caregiver
SWAN Rehab SouthWest Advanced Neurological	Coalition
Rehabilitation	Toll free (888) 737-7494
1190 E Missouri Ave., Suite 100	www.rewardingwork.org/state-resources/arizona.aspx
Phoenix, Arizona 85014	Assess by computer or telephone locating direct care and
(602) 393-0520	respite providers you hire privately and/or agencies located
swanrehab.com	throughout Arizona
	Access code: 444745

Rehabilitation Services – Inpatient	Social Services cont
Sante' Rehabilitation	Caring Voice Coalition
<u>www.santecares.com</u> Santé	Toll Free (888) 267-1440 (Patient Line)
Rehabilitation services serving Arizona in an state-	Program aimed at financial, emotional, educational support
of-the-art transitional rehabilitation facility	of people with chronic illnesses
including Medical Home Health, Palliative and	www.caringvoice.org
Hospice Care in the community. Serving – Mesa,	
Chandler, Scottsdale and Surprise location Coming	
soon – Tucson, AZ	<u> </u>
	Huntington's Disease Youth Organization
Healthsouth Valley of the Sun Rehab. Hospital	Chandler Swope, LICSW Director of Youth Services
10 Locations:	
Glendale, Mesa (2), Scottsdale, Tucson (2)	Cell: (202)674-4848 Email: chandler@hdyo.org
	Email: chandler@hdyo.org
Direct Admission	Visit the national website at www.hdyo.org
www.Healthsouthvalleyofthesun.com	Supporting young people around the world impacted by HD
	supporting young people around the trond impacted by 1.12
Cannabis Services	Prescription Financial Support Services
Southwest Medical Marijuana Evaluation Center	Xenazine Information Center or XIC.
Medical Clinic	(888) 882-6013
Phoenix Location: 12620 N Cave Creek Rd Suite 7,	They will work with you and the family on financial issues
Phoenix, AZ (480) 656-2119	regarding medication use
Scottsdale Location: 8010 E McDowell Rd, Suite	
105	
Scottsdale, AZ (480) 656-2119	
www.evaluationtoday.com	

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MJ Consulting, LLC	Miscellanies Supports websites
8540 AZ-69	RiJi Drinking Cups
Prescott Valley, AZ 86314	Dysphasia Products
(928) 772-2011	<u>www.epeciale.com</u>
www.mymjfamily.com	
	http://www.especialneeds.com
The Giving Tree Well Center	Lingraphica's Small Talk—there are several versions of this
Phoenix location: 21617 N. 9 <sup>th</sup> 21617 N 9th Ave	program and app; some focus on naming, some on syntax,
Phoenix, AZ (623) 242-9080	They are not all suitable for everyone, but there are free
Mesa location: 938 E. Juanita Ave., Mesa, AZ (480)	demos that people can test out:
272-9888	https://www.aphasia.com
www.givingtreeaz.com	
Medical Cannabis Location link	Free Cremation with Memorial Service
http://azmarijuana.com/map	Consider donate a body to science and today's technologies
	are contributed such as donating your body to science.
	Southwest Institute for Bi-Advancement) SWIBA
	Benefits: No Charges for cremation
	No cost for transportation,
	No cost for completing and filing for death certificates
	(recommended 5-7)
	No cost for return of donated remains for family
	Call SWIBA (480) 985-4900
Medical Cannabis Doctor link	
http://azmarijuana.com/doctors	
Arizona Dept. Of Health Services provides a half	
price discounts to those on public assistance, so	
that reduces cost by \$75.00 for the indivual.	

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Cannabis Advocacy  MomForce AZ — Contact Kathy Inman  (480) 619-0302  Advocating for Arizonans for Safe Access to  Cannabis  www.momforceaz.org <a href="https://www.youtube.com/watch?v=0kH2hjzJ2mg">https://www.youtube.com/watch?v=0kH2hjzJ2mg</a> Driving Assessments  DriveAble Solutions, Certified Driving Rehabilitation
(480) 619-0302 Advocating for Arizonans for Safe Access to Cannabis www.momforceaz.org <a href="https://www.youtube.com/watch?v=0kH2hjzJ2mg">https://www.youtube.com/watch?v=0kH2hjzJ2mg</a> Driving Assessments
Advocating for Arizonans for Safe Access to Cannabis www.momforceaz.org https://www.youtube.com/watch?v=0kH2hjzJ2mg  Driving Assessments
Cannabis www.momforceaz.org <a href="https://www.youtube.com/watch?v=0kH2hjzJ2mg">https://www.youtube.com/watch?v=0kH2hjzJ2mg</a> Driving Assessments
https://www.youtube.com/watch?v=0kH2hjzJ2mg  Driving Assessments
https://www.youtube.com/watch?v=0kH2hjzJ2mg  Driving Assessments
DriveAble Solutions, Certified Driving Renabilitation
Specialists (SO2) 242 222
(602) 840-2323
http://www.driveablesolutions.com/about-us/
Unsafe Driving Reporting
Arizona Mother Vehicle Dept.
http://www.azdot.gov/docs/default-source/mvd-
forms-pubs/96-0469.pdf
Reporting unsafe driver
to safely operate a motor vehicle.

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#### **Adaptive Technology**

Arizona Assistive Technology Exchange Program: Statewide, Phoenix-based

The goal of the Arizona Assistive Technology Exchange hosted by AzTAP is to put Assistive Technology (AT), adapted equipment or Durable Medical Equipment (DME) that is not currently being used into the hands of someone who can benefit from it.

Northern Arizona University 300 W. Clarendon Ave, Suite 475 Phoenix, AZ 85013

Phone (602) 728-9534 TTY: (602) 728-9536 Fax: (602) 728-9535

Toll-Free: (800) 477-9921 FREE

http://www.azatexchange.org/home.php

And the link to lending closets statewide:

#### http://www.azatreuse.org/search\_directory.php

#### **Prescription Drug Discount Card**

NeedyMeds makes it easy to send a family member or friend a drug discount card to help save up to 80% off the cash price of their prescriptions. Just click on the left navigation link that says "Send a family member or friend a NeedyMeds Drug Discount Card" under the red arrow.

#### Miscellanies Supports websites cont. . .

Proloquo2Go—This one is expensive, but has good features. It's a picture system that when the person presses the picture tile, a sentence is spoken aloud by the computer. This one is such an investment, I would recommend seeing a clinical speech-language pathologist for training with this app.:

http://www.assistiveware.com/product/prologuo2go

Seating supports websites cont...

**Broad Seating** 

http://www.brodaseating.com/

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## ARIZONA HUNTINGTON'S DISEASE RESOURCES

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http://www.needymeds.org/	
Arizona Rx Card - Free Statewide Prescription Assistance As a resident of <b>Arizona</b> , you and your family have access to a statewide Prescription Assistance Program (PAP). Create and print your <i>FREE</i> discount prescription drug card below. This card will provide you with Rx medication savings of up to 75% at more than 68,000 pharmacies across the country including <b>Safeway, Bashas, CVS/pharmacy, Target, Food City, Frys, Kmart, Osco, Walgreens</b> , and many more. You can create as many cards as you need. We encourage you to give cards to friends and family members. This card is pre-activated and can be used immediately!	Note: Xenazine manufactured by Lundbeck is no longer covered under Medicare Part B, and Hospice would have to cover 100%, which is highly unlikely. Patient assistance programs forms that need physicians/doctors office to complete. <a href="http://www.needymeds.com/">http://www.needymeds.com/</a>
Cooper Card Simple prescription drug discount card available to ANY Arizonan.	Hospice and Palliative Care Programs cont  Complete Hospice Care, Phoenix  Palliative Care Support Program
Many Arizonans – especially those without insurance – have been hit hard by the rising costs of medications. This card was created to give you a simple way to get	2728 N 24th St, Phoenix, AZ 85008 Phone:(602) 900-1793 Contact: Lori Kleinschmidt (602) 900-1793 completehospice.com

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substantial discounts on spiraling prescription drug prices.

As you evaluate discount cards, remember that the CoppeRX® Card is free:

#### **Free of Charge**

Every Arizonan is entitled to a free CoppeRX® Card. Link here **www.arizonarxcard.com** to sign up or call (888) 227-8315 FREE.

Maricopa County Board of Supervisors has launched a discount card program to help consumers cope with the high price of prescription drugs. Maricopa County is making free prescription drug discount cards available under a program sponsored by the National Association of Counties (NACo) offering a substantial savings off the retail price of commonly prescribed drugs. The cards may be used by all county residents, regardless of age, income, or existing health coverage, and are accepted at well over 80% of the county's pharmacies. The savings for the uninsured and underinsured residents of our county, and even those fortunate to have prescription coverage can use the card to save money on drugs that are not covered by their health plan. Residents do not have to be Medicare beneficiaries to be eligible for this program. To request a prescription:

Comprehensive Hospice

2111 E Highland Ave b425, Phoenix, AZ 85016

Phone: (602) 795-9705

Contact: John Schwantes (602) 795-9705

chpchospice.com

askmc@mail.maricopa.gov with your name and mailing address.	
https://www.maricopa.gov/publichealth/programs/rx/	
	HD Medical Alert Bracelets
	Features: Adjustable, lightweight, includes 4 waterproof
	inserts to write medical info. and emergency contact info.
	1-800-345-HDSA (4372) or visit:
	https://interland3.donorperfect.net/weblink/
	weblink.aspx?name=E5596&id=150
	Family Caregiver Emergency Alert Bracelets
	American Medical ID for the Caregiver
	http://www.americanmedical-id.com/extras/caregivers.php
	The bracelet states:
	Caregiver's Name
	I am a caregiver for my (relationship—mother, father, spouse, etc.)
	Care recipient's name
	Urgent needs and instructions for the recipient
	Who to contact in your absence
	Contact: 1-800-363-5985

Mental Health Integrated Associates <a href="http://www.integratedmha.com">http://www.integratedmha.com</a> 8130 East Cactus Road, Suite 520, Scottsdale, Arizona 85260 (480) 261-5015