



CITY OF SURPRISE
Veteran, Disability and Human Service Commission Meeting
16000 N. Civic Center Plaza
Surprise, AZ 85374
Wednesday, August 14, 2019 @ 6:00 PM
COUNCIL CHAMBERS

- A. Call To Order
- B. Roll Call
- C. Pledge of Allegiance
- D. Current Events and Reports
- E. Staff Reports
- F. Veterans, Disability and Human Services Commission

CALL TO THE PUBLIC:

INSTRUCTIONS: In order to address the Board\Commission, you will need to fill out a Call to the Public Form available at the front counter, and then turn it in to the Secretary before the meeting begins.

Note: A.R.S. 38-431.01(H) - During this time members of the public may address the Board\Commission only on issues within the jurisdiction of the Board\Commission which are not an item on the agenda. At the conclusion of the open call, the Board\Commission may respond to criticism, may ask staff to review the matter or may ask that the matter be put on a future agenda. No discussion or action shall take place on any item raised.

CONSENT AGENDA:

REGULAR AGENDA ITEM - PUBLIC HEARING:

REGULAR AGENDA ITEM - NON-PUBLIC HEARING:

- | | | | |
|----|----------|--|--|
| 1. | Internal | Consideration and action pertaining to approval of the June 12, 2019 Veterans, Disability and Human Services Commission meeting minutes. | None

Yvonne Lopez
Human Svcs and
Comm Vitality |
| 2. | Internal | Consideration and action pertaining to the nomination and election of the Veterans, Disability and Human Services Commission Chair. | None

Paul Bernardo
Human Svcs and
Comm Vitality |
| 3. | Internal | Consideration and action pertaining to the nomination and election of the Veterans, Disability and Human Services Commission Vice Chair. | None

Paul Bernardo
Human Svcs and
Comm Vitality |
| 4. | Citywide | Presentation and discussion pertaining to the Surprise Community Needs Assessment. | None

Paul Bernardo
Human Svcs and
Comm Vitality |

- | | | | |
|----|----------|--|--|
| 5. | Citywide | Presentation and discussion pertaining to an overview of The Arc of Arizona organization. | None |
| | | | Paul Bernardo
Human Svcs and
Comm Vitality |
| 6. | Citywide | Presentation and discussion pertaining to an overview of Transnational Genomics Research Institute (TGEN). | None |
| | | | Paul Bernardo
Human Svcs and
Comm Vitality |
| 7. | Citywide | Presentation and discussion pertaining to an update of the Community Resource Fair. | None |
| | | | Paul Bernardo
Human Svcs and
Comm Vitality |

G. Other Business and Future Agenda Items

H. Executive Session

For information purposes: Upon a public majority vote of a quorum ("Commission"), the Commission may hold an executive session, which will not be open to the public, but for only the following purposes: discussion or consideration of records exempt by law from public inspection (A.R.S. §38-431.03(A)(2));

or discussion or consultation for legal advice with the attorney or attorneys of the public body (A.R.S. §38-431.03(A)(3)).

Confidentiality Requirements: Pursuant to A.R.S. §38-431.03(C)(D), any person receiving executive session information pursuant to A.R.S. §38-431.02 shall not disclose that information except to the Attorney General or County Attorney or by agreement of the Commission, or as otherwise ordered by a court of competent jurisdiction.

The Commission may vote to hold an executive session for the purpose of obtaining legal advice from the Commission's attorney on any matter listed on the agenda pursuant to A.R.S. § 38-431.03(A)(3).

I. Adjournment

SHERRY ANN AGUILAR, CITY CLERK, MMC

POSTED: posted on Friday, August 2, 2019 @ 2:55 P.M.

SPECIAL NOTE: PERSONS WITH SPECIAL ACCESSIBILITY NEEDS, INCLUDING LARGE PRINT MATERIALS OR INTERPRETER, SHOULD CONTACT THE CITY CLERK'S OFFICE @ 623.222.1200 OR TTY 623.222.1002, BY NO LATER THAN 24 HOURS IN ADVANCE OF THE REGULAR SCHEDULED MEETING TIME.



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Yvonne Lopez, Administrative
Specialist Sr

Submitting Department: Human Svcs and Comm Vitality District: Internal

Staff Recommendations: None

Consent: No	Regular: Yes	Public Hearing: No	Report/Discussion: No
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Agenda Wording:

Consideration and action pertaining to approval of the June 12, 2019 Veterans, Disability and Human Services Commission meeting minutes.

Motion:

I move to approve the June 12, 2019 Veterans, Disability and Human Services Commission meeting minutes.

Background:

Objective Analysis:

Policy Compliant:

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:

1. 06.12.19 VDHS Commission Minutes
-

**CITY OF SURPRISE
VETERANS, DISABILITY, AND HUMAN SERVICES COMMISSION**

MEETING MINUTES

June 12, 2019 / 6:00 PM

**COUNCIL CHAMBERS
16000 North Civic Center Plaza
Surprise, AZ 85374**

CALL TO ORDER.

Chair George Van de Langeryt called the Veterans, Disability and Human Services Commission Meeting to order at 6:00 p.m. at Surprise City Hall, 16000 North Civic Center Plaza, Surprise, Arizona 85374, on June 12, 2019.

A. ROLL CALL

In attendance were Chair George Van de Langeryt, Vice Chair Jacob Thomas, and Commissioners Shawna Daigle, Steffen Hanzel, Bruce Hertzog, Dan Moore, Tom Short, and Andrew Witzel. Kathryn Chandler arrived at 6:08PM. Commissioner Karissa Perry was absent.

STAFF PRESENT:

Human Service & Community Vitality Director Seth Dyson, Community Partnerships Manager Paul Bernardo, Assistant City Attorney Hobie Wingard, Planner Hobart Wingard, Sr., Financial Analyst Deb Perry and Commission Liaison Yvonne Lopez

COUNCIL MEMBERS PRESENT:

Councilmember Judd.

B. PLEDGE OF ALLEGIANCE

C. CURRENT EVENTS REPORT

Chair Van de Langeryt announced the following upcoming events:

- On June 13, 2019 at 11:00am to 3:00pm, The Disabled American Veterans (DAV) and Recruit Military will host a Veterans Job Fair at the Gila River Arena
- On Friday, June 14, 2019 the Arizona Department of Veterans Services will hold a Military and Veterans Women's Summit at Tempe Mission Palms Hotel & Conference Center. For more information, please visit AZ Veterans website.
- Fly your flag on Friday, June 14, 2019, in observance of Flag Day. It is also the 244th Birthday of the United States Army.
- On June 6, interviews were conducted for the Veterans, Disabilities and Humans Services commission vacancy. Vice Mayor Winters, Councilmember Remley and Councilmember Sanders were on the nomination committee. Thirteen applications were received. Eleven interviews were conducted and a candidate has been selected.

- Commissioner Witzel stated on June 28, 2019 at El Mirage City Hall from 9:00AM to Noon Maricopa County AZ@Work will be hosting a Job Fair for Industrial and Manufacturer Employers in partnership with the City of EL Mirage.

D. STAFF REPORT

None

CALL TO THE PUBLIC:

Chair Van de Langeryt opened the call to the public to discuss any items not on the agenda. Hearing no comments, Chair Van del Langeryt closed the call to the public

CONSENT AGENDA:

None

REGULAR AGENDA ITEMS NON-PUBLIC HEARING:

Item 1 – Internal – Consideration and action pertaining to the May 8, 2019 Veterans, Disability and Human Services Commission Meeting minutes.

Commissioner Moore made a motion to approve the May 8, 2019 Veterans, Disability and Human Services Commission Meeting minutes. Commissioner Hertzog seconded the motion. The motion passed with eight yes votes.

Item 2 – Internal – Consideration and action pertaining to the FY2020 Veterans, Disability and Human Services Commission regular meeting schedule.

Chair Van de Langeryt announced there will not be a July2019 meeting and the Commission will convene every second Wednesday of every month at 6pm, with an exception of a work session for Community Development Block Grant Program (CDBG) training on August 7, 2019. Commissioner Hertzog made a motion to approve the FY2020 Veterans, Disability and Human Services Commission regular meeting schedule. Commissioner Hanzel seconded the motion. The motion passed with eight yes votes.

Item 3 – Citywide - Presentation and discussion pertaining to the update of Community Resource Fair.

Community Partnerships Manager Paul Bernardo introduced Mike Homco and Jeff Swanson, Executive directors with One Step Beyond, Inc.

Mr. Homco and Mr. Swanson gave a brief overview of the support services and resources they provide to individuals who have intellectual disabilities. They gave a detailed report on their many programs and services.

Commissioner Witzel asked what type of industries are they looking for to provide employment and what industry can we refer to One Step Beyond to help their individuals. Mr. Homco stated that it is not a specific industry but a partnership to properly match a member with the business.

Chair Van de Langeryt asked what type of facilities does One Step Beyond have here in surprise. Mr. Homco stated that One Step Beyond has four campus buildings located on Greenway and Reems.

Chair Van de Langeryt asked what was the age group that they serve. Mr. Homco stated they serve ages 3 years to 99 years. Certain programs are more for adults, like the employment and life skills programs.

Commissioner Short asked if there were federal or state programs that provide employers incentives to employ individuals with disabilities. Mr. Homco stated that he believed there are some tax benefits. He mentioned that One Step Beyond helps employers by having a job coach to support the members, work with supervisors and help the member master the task until the member can do it independently.

Commissioner Hanzel asked if there was one thing the City of Surprise or the community could do for their organization what would that be. Mr. Homco stated that the City and community could help their members by being more accepting and inclusive.

Commissioner Hertzog stated that he is an employee of One Step Beyond and commended them for their services and programs. He encourages the community to attend the One Step Beyond theater group performances.

Item 4 – Citywide - Presentation and discussion pertaining to an overview of the American Patriot Service Corp.

Chair Van de Langeryt introduced Rick Nelson from American Patriot Service Corp.

Mr. Nelson gave a detailed report on their organization and how many veterans they've supported in receiving aid and attendance benefits.

Commissioner Witzel asked who provides the training to their service officers and how are they certified. Mr. Nelsen explained that their service officers are trained by an Attorney they have on staff who is accredited by VA.

Commissioner Hanzel asked how does someone get in touch with their organization and if there was one thing the City of Surprise or the community could do for their organization what would that be. Mr. Nelsen stated that they can be reached by contacting Seth Dyson, Director of Human Service and Community Vitality and they can be found on www.acspnp.org. He stated that the City of Surprise and the community could help them succeed by referring people who need the service.

Commissioner Chandler wanted to make Mr. Nelson aware of the Military and Veteran success center and she appreciated Mr. Nelson's passion.

Mr. Bill Smith, who is also involved with American Patriot, spoke about the Channel 12 story that recently aired regarding the aid and attendance benefit.

Item 5 – Citywide - Consideration and action pertaining to the update of the community resource fair.

Community Partnerships Manager Paul Bernardo and Vice Chair Thomas gave updates on the progress of the community resource fair working group. The event will take place on

Saturday, October 5, 2019 from 10:00am to 2:00 pm on the ground level of the City Hall parking structure and in the City Hall courtyard. The group has a list of 75 nonprofit organizations they are asking to attend the event.

Commissioner Daigle mentioned that the organizations are responding very positive to joining our event.

Vice Chair Thomas mentioned that a few organizations attended one of our events in the past and are looking forward to attending this year's event.

Chair Van de Langeryt mentioned that our vendors need to know this is not an event to promote fundraising.

Commissioner Witzel mentioned the resource fair would be an opportunity to promote an upcoming job fair that will follow a week after.

Item 6 – Citywide - Consideration and action pertaining to the update of the community needs assessment.

Director Seth Dyson gave an update on the community needs assessment. A firm has been selected and is under contract. The contract runs thru January 2020 with a final report due in November.

Commissioner Hanzel asked if the original timeline remains the same. Director Dyson stated that the timeline has not changed.

OTHER BUSINESS AND FUTURE AGENDA ITEMS:

The Commission had an open discussion regarding items they would like added to future agendas. Items included:

- AZ Commission for the Deaf and Hard of Hearing

ADJOURNMENT:

Hearing no further business, Chair Van de Langeryt adjourned the Veterans, Disability and Human Services Commission meeting at 7:19 p.m.

Paul Bernardo
Community Partnerships Manager

George Van de Langeryt
Veterans, Disability and Human Services Commission Chair

The foregoing instrument is a full, true and correct copy of the original document on file in the office of the City Clerk, City of Surprise, Arizona.

ATTEST BY:

Yvonne Lopez, Commission Liaison

DATE:



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm District: Internal
Vitality

Staff Recommendations: None

Consent: No	Regular: No	Public Hearing: No	Report/Discussion: No
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Agenda Wording:

Consideration and action pertaining to the nomination and election of the Veterans, Disability and Human Services Commission Chair.

Motion:

I move to elect (insert name here) to the position of Chair of the Veterans, Disability and Human Services Commission.

Background:

Nominations will take place and a paper ballot will be available in the event numerous commissioners are nominated. A motion, second, and a roll call vote will follow the paper ballots.

Objective Analysis:

This action allows for the nomination and election of a chair for the Commission.

Policy Compliant:

This action is compliant with the City and Council policies.

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm
Vitality

District: Internal

Staff Recommendations: None

Consent: No

Regular: No

Public Hearing: No

Report/Discussion: No

Agenda Wording:

Consideration and action pertaining to the nomination and election of the Veterans, Disability and Human Services Commission Vice Chair.

Motion:

I move to elect (insert name here) to the position of Vice Chair of the Veterans, Disability and Human Services Commission Vice Chair.

Background:

Nominations will take place and a paper ballot will be available in the event numerous commissioners are nominated. A motion, second, and a roll call vote will follow the paper ballots.

Objective Analysis:

This action allows for the nomination and election of a vice-chair for the Commission.

Policy Compliant:

This action is compliant with City and Council policies.

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm
Vitality

District: Citywide

Staff Recommendations: None

Consent: No

Regular: Yes

Public Hearing: No

Report/Discussion: No

Agenda Wording:

Presentation and discussion pertaining to the Surprise Community Needs Assessment.

Motion:

Discussion Only.

Background:

The presentation provides an introduction to I&E Consulting and an overview of the Community Needs Assessment.

Objective Analysis:

This introduction will provide the public with the background of I&E Consulting and overview for the Community Needs Assessment.

Policy Compliant:

This presentation is compliant with City and Council Policies.

Financial Impact:

This item will have financial impact on the FY20 budget.

Budget Impact:

The total cost for the community needs assessment will be \$48,960.00 which will be taken from the FY20 budget and CDBG funds.

FTE Impact:

N/A

ATTACHMENTS:



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm
Vitality

District: Citywide

Staff Recommendations: None

Consent: No

Regular: Yes

Public Hearing: No

Report/Discussion: No

Agenda Wording:

Presentation and discussion pertaining to an overview of The Arc of Arizona organization.

Motion:

Discussion only.

Background:

This presentation will provide information and a brief overview of The Arc of Arizona organization and allows the Commission an opportunity to discuss this item.

Objective Analysis:

This presentation will provide information and an overview of The Arc of Arizona.

Policy Compliant:

This presentation is compliant with City and Council policies.

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:

1. The ARC AZ presentation



For people with intellectual and developmental disabilities

A National Leader for Change

- 60+ years of activism, advocacy, and education
- At forefront of progress for children and adults
- Serving all intellectual and developmental disabilities
- Legislative and policy priorities:
 - Quality of life
 - Education services
 - Accessibility
 - Health care
 - Transportation
 - Housing
 - Employment



A History of Name Changes



- 1953 - 1973: National Association for Retarded Children (NARC)
- 1973 - 1981: National Association for Retarded Citizens (NARC)
- 1981 - 1992: Association for Retarded Citizens of the United States (ARC)
- 1992 - Present: The Arc of the United States (The Arc)

A History of Accomplishments

1950s

- The Arc is founded as a national organization
- The Arc becomes the first organization to put money into research on intellectual and developmental disabilities

1960s

- The Arc helps expose the link between lead poisoning and brain damage in infants and children

A History of Accomplishments

1950s

- The Arc is founded as a national organization
- The Arc becomes the first organization to put money into research on intellectual and developmental disabilities

1960s

- The Arc helps expose the link between lead poisoning and brain damage in infants and children

A History of Accomplishments

1970s

- Public Law 94-142, Education for All Handicapped Children Act, guarantees free appropriate public education for all children with disabilities
- Supplemental Security Income (SSI) program to support persons with severe disabilities who have little or no income
- Section 8 Assisted Housing program to meet the housing needs of low income families and individuals with disabilities
- Establishment of the Medicare and Medicaid programs
- Passage of the Developmental Disabilities Act
- Groundbreaking study shows infant under-nutrition as a cause of developmental disabilities and links between poverty and developmental disabilities
- Kenneth Jones, M.D., defines the disorder Fetal Alcohol Syndrome

A History of Accomplishments

1970s

- Public Law 94-142, Education for All Handicapped Children Act, guarantees free appropriate public education for all children with disabilities
- **Supplemental Security Income (SSI) program to support persons with severe disabilities who have little or no income**
- Section 8 Assisted Housing program to meet the housing needs of low income families and individuals with disabilities
- **Establishment of the Medicare and Medicaid programs**
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A History of Accomplishments

1980s

- Civil Rights for Institutionalized Persons Act gives Justice Department statutory authority to protect rights of institutionalized individuals
- Creation of Supported Employment program within Rehabilitation Act
- "Baby Doe" Amendment protects newborns with disabilities from being denied life saving medical treatment
- Work incentives in Social Security Act allow more individuals with disabilities to work
- Passage of Technology-Related Assistance Act to develop statewide assistive technology programs
- Disability added as a protected class under Fair Housing Act
- Establishment of Disabilities Prevention Program at Centers for Disease Control.

A History of Accomplishments

1980s

- **Civil Rights for Institutionalized Persons Act gives Justice Department statutory authority to protect rights of institutionalized individuals**
- Creation of Supported Employment program within Rehabilitation Act
- "Baby Doe" Amendment protects newborns with disabilities from being denied life saving medical treatment
- **Work incentives in Social Security Act allow more individuals with disabilities to work**
- **Passage of Technology-Related Assistance Act to develop statewide assistive technology programs**
- **Disability added as a protected class under Fair Housing Act**
- Establishment of Disabilities Prevention Program at Centers for Disease Control.

A History of Accomplishments

1990s

- The Arc is a leader among national disability groups to advocate for the landmark Americans with Disabilities Act
- Medicaid buy-in option for families whose income is somewhat higher than basic eligibility ceiling
- National media and advertising campaign to raise awareness about dangers of alcohol consumption during pregnancy
- Fetal Alcohol Syndrome Prevention and Education Act passed by Congress
- New publication, Genetic Issues in Developmental Disabilities, initiated as part of The Arc's Human Genome Project
- The Arc is involved in drafting first national family support legislation

A History of Accomplishments

1990s

- **The Arc is a leader among national disability groups to advocate for the landmark Americans with Disabilities Act**
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- The Arc is involved in drafting first national family support legislation

A History of Accomplishments

So far this century...

- Students with disabilities covered in educational accountability system under No Child Left Behind Act
- Drafting of United Nations Convention on the Rights of Persons with Disabilities
- National FindFamily Registry, online database to help families reconnect with formerly institutionalized relatives with whom they lost touch long ago
- New provisions in Individuals with Disabilities Education Act and Higher Education Act help students move from public schooling to higher education, employment and adult life.
- National Housing Trust Fund established to provide over 50,000 new public housing vouchers for people with disabilities
- National effort denounces negative and inaccurate portrayal of people with I/DD in popular media and seeks end to use of “‘R’ word”
- Affordable Care Act ensures baseline health benefits for persons with disabilities
- ABLE Act passage provides new savings opportunity without jeopardizing government benefits

A History of Accomplishments

So far this century...

- Students with disabilities covered in educational accountability system under No Child Left Behind Act
- Drafting of United Nations Convention on the Rights of Persons with Disabilities
- **National FindFamily Registry, online database to help families reconnect with formerly institutionalized relatives with whom they lost touch long ago**
- **New provisions in Individuals with Disabilities Education Act and Higher Education Act help students move from public schooling to higher education, employment and adult life.**
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- **National effort denounces negative and inaccurate portrayal of people with I/DD in popular media and seeks end to use of “R” word**
- **Affordable Care Act ensures baseline health benefits for persons with disabilities**
- **ABLE Act passage provides new savings opportunity without jeopardizing government benefits**

The Arc in Arizona Today

- The Arc of Arizona (State Chapter)
 - Advocacy, Policy and Education
 - Statewide outreach
 - Unique programs & events (Wings for Autism, Sprout Film Festival)
- 11 Independent Local Chapters
 - Day treatment
 - Employment/training
 - Habilitation
 - Group homes
 - Advocacy



The Arc of Arizona – Key Accomplishments

(2013-2019)



- Insertion of People-First Language in reference to individuals with disabilities in all state documents
- Limitations on use of Restraint & Seclusion methods of discipline in schools
- Restoration of annual dental benefit for ALTCS members
- Establishment of state ABLE savings program
- Increased oversight & monitoring of Developmental Homes
- Addition of persons with I/DD to Silver Alert System
- Changing tables in government buildings
- Heightened protections for vulnerable adults

The Arc of Arizona – Key Priorities

- Appropriate & adequate health care
- Education & Transition
- Employment opportunities for persons with I/DD
 - Integrated settings
 - Competitive wages
- Self-determination & Supported Decision-Making
- Future planning
- Protection from abuse, neglect & exploitation



Achieve with us.®

www.arcarizona.org



CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm
Vitality

District: Citywide

Staff Recommendations: None

Consent: No

Regular: Yes

Public Hearing: No

Report/Discussion: No

Agenda Wording:

Presentation and discussion pertaining to an overview of Transnational Genomics Research Institute (TGEN).

Motion:

Discussion only.

Background:

This presentation will provide information and a brief overview of the programs and services of Transnational Genomics Research Institute (TGEN) and allows the commission an opportunity to discuss the item.

Objective Analysis:

This presentation will provide information and an overview of Transnational Genomics Research Institute (TGEN).

Policy Compliant:

This presentation is compliant with City and Council policies.

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:

1. TGen Presentation

TRANSLATIONAL GENOMICS RESEARCH INSTITUTE

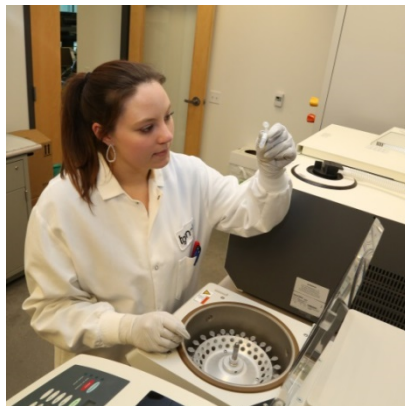
ESTABLISHED JUNE 26, 2002

Keri Ramsey, RN
Clinical Co-Director C4RCD

What is TGen?

TGen is a private, non-profit research institute performing genomic research on complex diseases and disorders including: cancer, neurological disease, diabetes, and infectious disease.

TGen's mission is to make and *translate* discoveries into diagnostics, therapies and treatments tailored to the unique needs of individual patients.



World-Class Leadership

“From the laboratory bench to the patient bedside”



*Jeffrey M. Trent, PhD,
FACMG
TGen President and
Research Director*

To harness knowledge from science to produce novel drugs, devices and treatment options for patients.



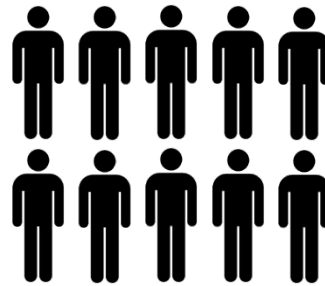
*Daniel D. Von Hoff, MD,
FACP
TGen Physician-in-Chief and
Distinguished Professor*



The Human Genome Project 1993 - 2003



Precision/ Translational Medicine



Next Generation Sequencing



2001



2019

Research Areas

Neurological Diseases/Disorders

- ALS
- Alzheimer's Disease
- Autism
- Parkinson's Disease
- Migraines
- Depression and Bipolar Disorder
- Rare childhood diseases

Infectious Disease

- Antibiotic resistance
- Microbiomics
- Valley Fever, E. coli, MRSA

Cancer

- Breast cancer
- Ovarian cancer
- Lung cancer
- Pancreas cancer
- Adrenocortical carcinoma
- Skin cancer
- Brain cancer
- Sarcomas
- Multiple myeloma

Metabolic disease

- Diabetes

Drug Discovery

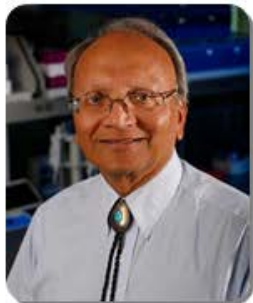


CENTER FOR RARE CHILDHOOD DISORDERS

TGen's Center for Rare Childhood Disorders



C4RCD Team



Vinodh



Matt



Keri



Meredith



Sampath



Newell



Liz



Ignazio



Cherae



Chris



Marcus



Wayne



Lori



Szabi

Background

- **Rare Disorders**
 - There are approximately 7,000 rare disorders
 - An estimated 1 out of 150 children is born with a rare genetic disorder.
 - Rare disease patients and families spend immeasurable time and money, often undergoing invasive, painful tests, to find an accurate diagnosis.
- **What We Do**
 - Expand access to genomic medicine
 - First and only center of its kind in the Southwest devoted to understanding, diagnosing and treating rare and complicated childhood disorders
 - Treated over 600 patients worldwide; 40% successful diagnosis rate
 - Treatments based on a patient's individual genetics
 - Educate public
 - Disease discovery



Who We Help

624 rare disease patients worldwide have had genetic testing, analysis at TGen's Center for Rare Childhood Disorders since 2012



1,615

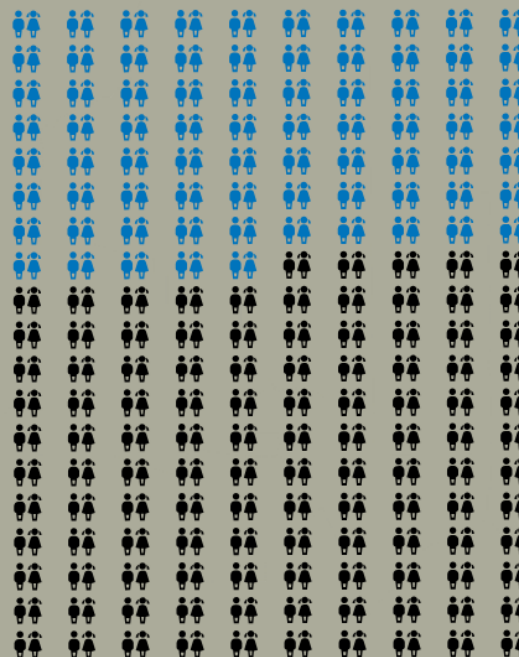
individuals have had genetic testing or analysis at the Center, as TGen also sequences the parents' DNA to look for disease-causing genetic mutations that could have been passed to the child or any siblings.

467

are from Arizona

75%

did **not** have insurance plans that cover genomic testing. TGen provides this testing at **no cost** to these families.



40% of TGen's patients receive a diagnosis, compared to **25%** in a typical clinic.

HOPE & ANSWERS

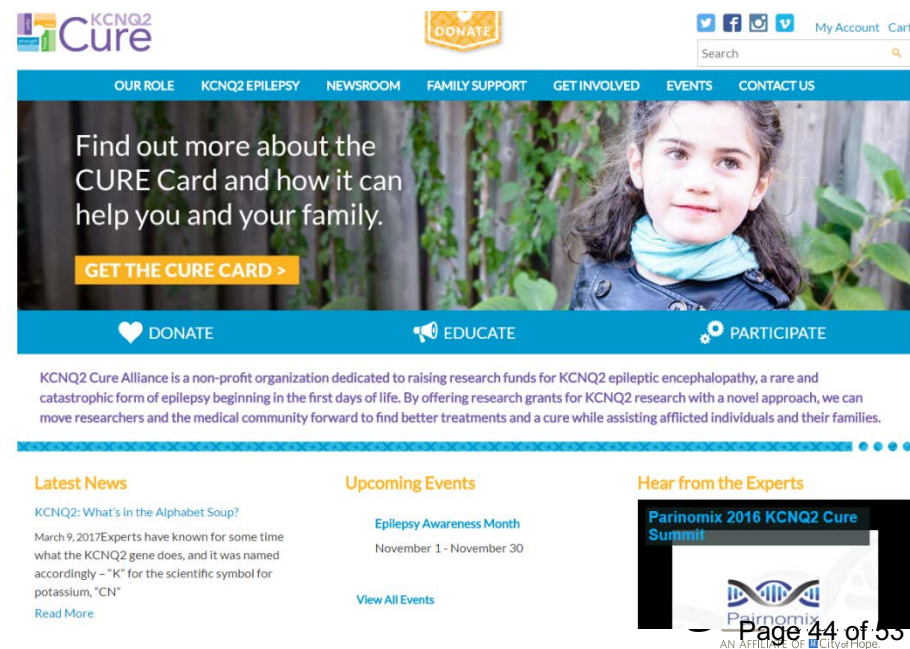
tgen
AN AFFILIATE OF City of Hope

How can genetic testing help families

- Guide treatment options
 - Selection of specific medications and an indication of how someone will respond to therapy (epilepsy medications, Ketogenic diet)
- Confirm a specific diagnosis
 - Enable participation in clinical trials
- Prevent or limit unnecessary treatment or invasive procedures and their associate costs
 - Muscle biopsy, MRIs, EMG, surgeries
- Predict the course of an illness
 - Natural history studies

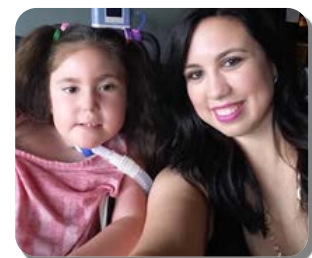


- Family planning
 - Preimplantation Genetic Diagnosis, Chorionic Villus Sampling
- Social Networking
- Creation of Patient Registries



Clinical Trial Update

- Tuberous Sclerosis Complex
 - CRAD001M2304 EXIST 3 (Novartis)
 - March 2015 - May 2018
 - CRAD001M2X02B (Novartis)
 - May 2018
 - AUCTA-UAP006-PH2 (Aucta Pharmaceuticals)
 - June 2019
- Rett syndrome
 - Neuren Pharmaceuticals
 - October 2019



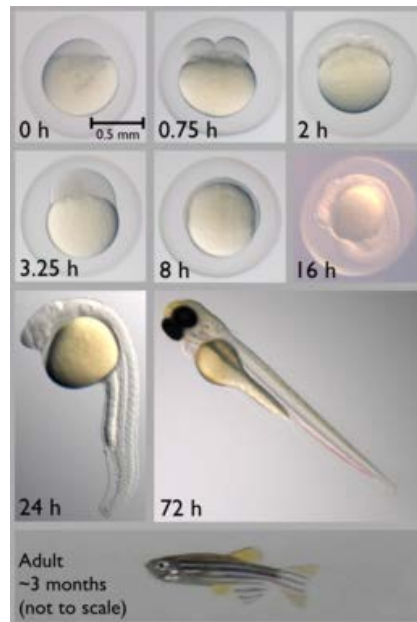
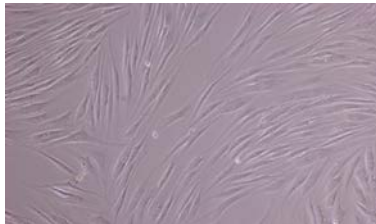
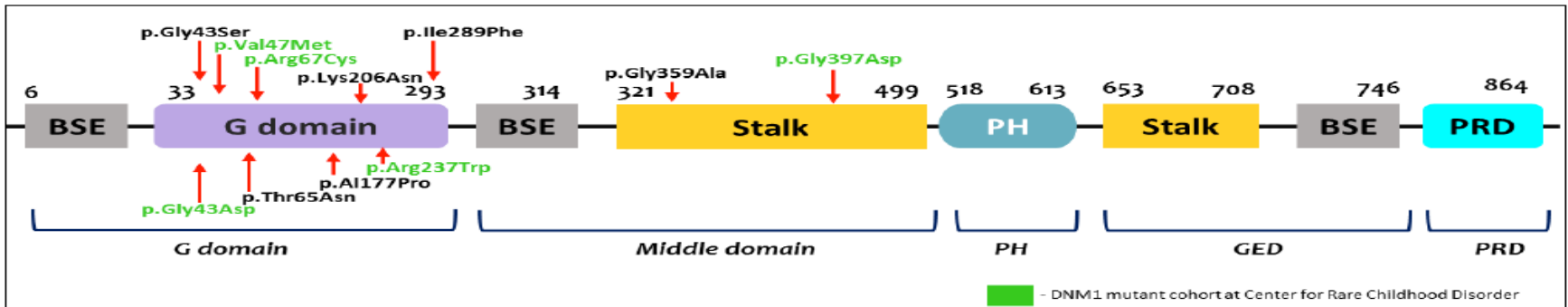
Research Beyond a Diagnosis



DNM1 gene mutation

- Mitochondrial encephalomyopathy with complex I deficiency
- Epilepsy (Lennox-Gastaut syndrome); started as infantile spasms; variety of seizures including persistent myoclonic seizures, spasm-like episodes where he will suddenly drop his head, flex his trunk and abduct his arms, complex partial seizures
- Hypotonia
- Cortical visual impairment and esotropia

DNM1 mutations in Epilepsy



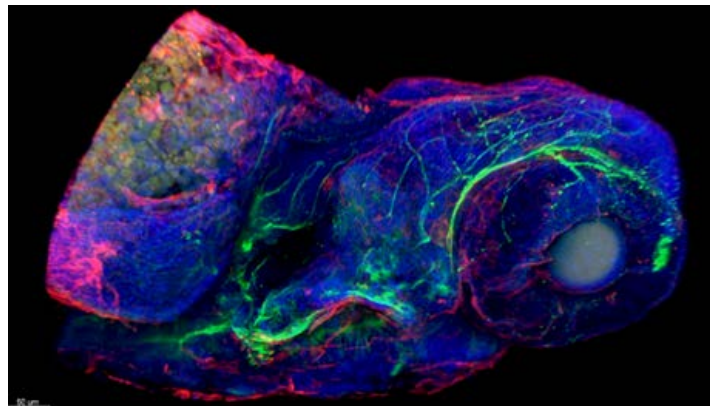
Zebrafish Epilepsy by inhibiting DNM1



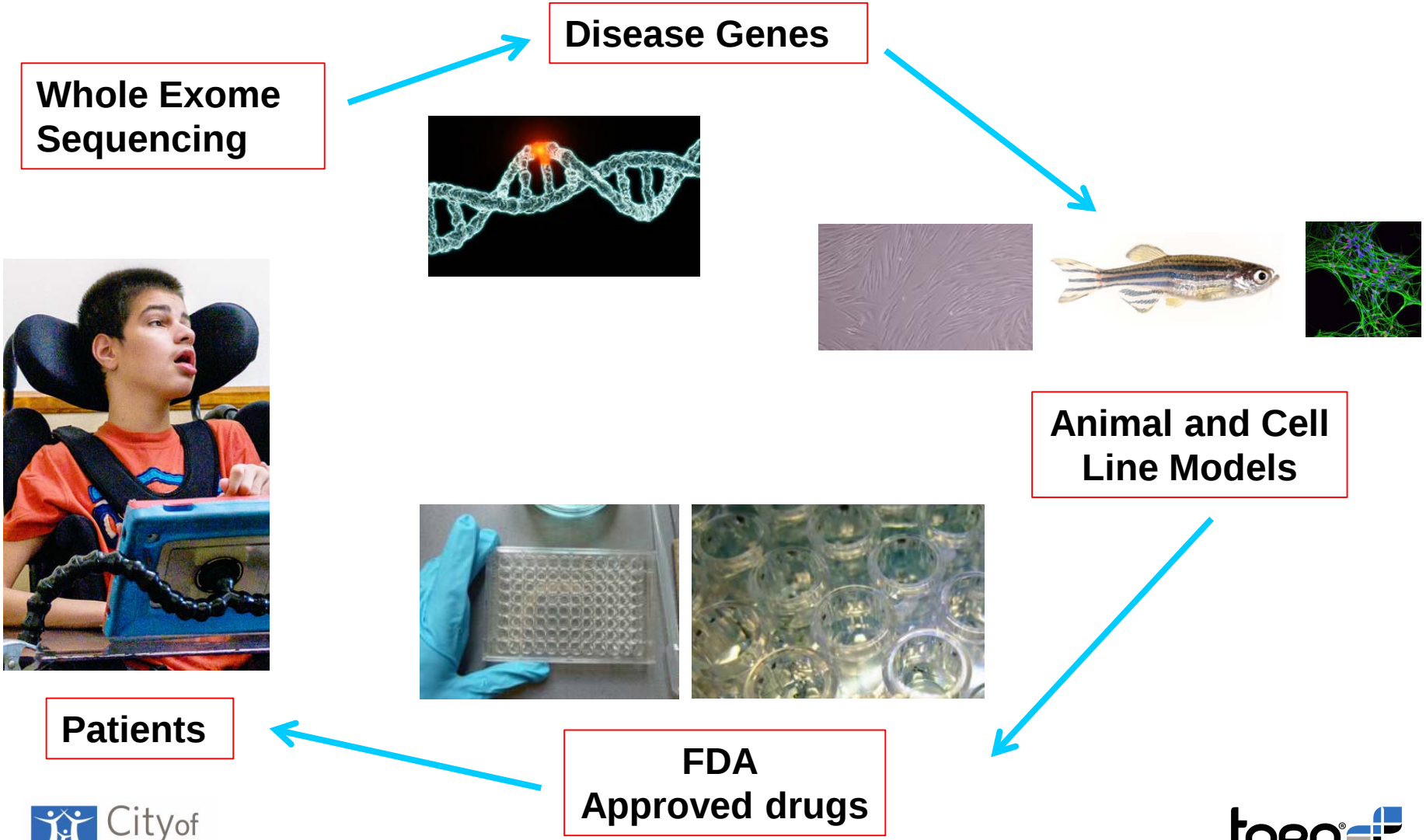
Video



Video



Personalized Medicine



Therapeutic Initiatives



- Collaboration between TGen C4RCD and COH
 - COH has developed a unique class of stem cell-derived nonpathogenic virus, hematopoietic stem cell-derived adeno-associated virus vector (AAVHSC) (Dr.Saswati Chatterjee, Ph.D. Professor, Department of Surgery)
 - Gene Therapy in Rett Syndrome, a neurodevelopmental disorder causing intellectual disability and seizures in girls
 - Research in patient cell lines and animal models



Inspiration





CITY OF SURPRISE
Veteran, Disability and Human Service Commission
Meeting

Council Meeting Date: August 14, 2019

Contact Person: Paul Bernardo, DIR-
GOV&COMM PTNRSP

Submitting Department: Human Svcs and Comm
Vitality

District: Citywide

Staff Recommendations: None

Consent: No

Regular: Yes

Public Hearing: No

Report/Discussion: No

Agenda Wording:

Presentation and discussion pertaining to an update of the Community Resource Fair.

Motion:

Discussion Only.

Background:

The presentation provides the background and updates for the Community Resource Fair.

Objective Analysis:

This presentation provides the background and updates for the Community Resource Fair.

Policy Compliant:

This presentation is compliant with City and Council policies.

Financial Impact:

N/A

Budget Impact:

N/A

FTE Impact:

N/A

ATTACHMENTS:
