Nevada Rare Disease Advisory Council (RDAC) Needs Assessment

Background: The be placed on the first screen when some clicks the assessment button

The Nevada Rare Disease Advisory Council (RDAC) is seeking survey participants to help identify the extent of rare disease(s) in Nevada. These survey results will be used to improve quality of care and to advise state agencies on research, diagnosis, treatment, and educational needs relating to rare diseases.

A rare disease is defined as any disease which affects fewer than 200,000 people in the United States and is known to be substantially under-diagnosed and unrecognized because of the lack of adequate diagnostic and research information, including diseases known as “orphan diseases” for research purposes. The RDAC was created by the passage of Senate Bill 315 during 2019 Nevada legislative session. The council is composed of medical and public health professionals, community advocates, and community members with experience in rare diseases.

By completing this survey, Nevada will be better positioned to assist those living with a rare disease. We are asking Nevadans affected by rare diseases to complete the survey as soon as possible to help us better understand demographics, progression and treatment, availability and quality of care, and other needed resources.

The survey will be available at www.nvrdac.org . We will create a QR code as well so this can be completed on a mobile devise as well.

NEXT Screen Button here

Next section

The purpose of this project is to better understand the experiences of individuals, family members and caregivers of people with rare disease(s), especially with respects to accessing care and difficulties with navigating the healthcare system in Nevada. The project consists of an online questionnaire which may take as long as 20-30 minutes to complete.

Individuals completing the survey must be 18 years of age or older to participate. This project is intended for people who live in Nevada or receive medical care in Nevada. Individuals with a rare disease(s), caregivers and/or family members of those with rare disease(s) are eligible to participate in the survey.

All information obtained is anonymous and will remain confidential. No questions will require identifying information that will lead back to a participant. **Survey findings will only be reported in the aggregate and be used to guide policies and services related to rare diseases in Nevada.** Participation in the survey is voluntary and there is no financial compensation for participation.

By proceeding with the survey, you recognize and accept the above information and consent to your responses being included in the project.

NEXT Screen Button here

Next section

Thank you for agreeing to take the Nevada RDAC Needs Assessment Survey!

We will ask you a series of questions about your/your family member's background, rare disease(s), the way you/they obtain medical care and information about your disease(s), and your/their socioeconomic concerns. We are interested in understanding your experience accessing medical care and any difficulties related to the healthcare system in Nevada and rare disease(s).

For this survey, a caregiver is a person who provides ongoing care or assistance to another person living with a rare disease. Caregivers are often family members of a person living with a rare disease. A paid support worker is a person who is paid to provide ongoing care or assistance to another person living with a rare disease.

NEXT Screen Button here

Next Section

We are going to start by asking you about the demographics of the person with the rare disease(s) and their households.

Is the person completing this survey?

- ○ A person living with a rare disease.
- ○ A relative/caregiver of a person with a rare disease
- ○ A parent of a child with a rare disease
- ○ A paid support worker
- ○ Other (please describe)
  - ○ TEXT BOX HERE FOR OTHER

Is the person completing this survey aged 18 years or older?

- ○ Yes
- ○ No (This survey should be completed by an adult at least 18 years old)
  - ○ SURVEY STOPS HERE IF NO IS CHECKED

Is the person with the rare disease a child (under 18) or an adult (18 or older)?

    ○ Child
    ○ Adult

What year was the person with rare disease born?

- ○ Drop down menu with years placed here.

NEXT Screen Button here

Next section

What is the race/ethnicity of the person with the rare disease? Select all that apply.

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Hispanic or Latino/a
- ○ Middle Eastern
- ○ Mixed Race
- ○ Native Hawaiian or Pacific Islander
- ○ While or Caucasian
- ○ Other
  - ○ TEXT BOX FOR OTHER HERE

Is the person with the rare disease:

- ○ Female
- ○ Male
- ○ Non-Identified

What is the marital/partnership status of the person with the rare disease?

- ○ Single (never been married)
- ○ Dating/ in a relationship
- ○ Married or partnered.
- ○ Divorced or Separated
- ○ Widowed

NEXT Screen Button here

Next Section

What is the highest level of education obtained by the person with the rare disease?

- Some elementary school or less- if this box is checked a drop down pop up with the following:
  - Homeschooled
  - Public School
  - Private School
- Some high school or less
- Some college
- Associated or technical degree
- Bachelor's degree
- Some graduate school
- Graduate degree

What is the approximate household income of the person with the rare disease?

- Under $20,000
- $20,000-$39,000
- $40,000-$59,000
- $60,000-$79,000
- $80,000-$99,000
- Over $100,000

NEXT Screen Button here

Next Section

The person with the rare disease lives in a:

- Large city (>100,000 residents)
- Medium city (>50,000-100,000 residents)
- Small town (>1,000-49,999 residents)
- Rural area (outside of a town or city: less than 1,000 residents)

Does the person with the rare disease (select all that apply):

- ○ Work full-time.
- ○ Work part-time.
- ○ Volunteer
- ○ Attend school/college/university.
- ○ Not work because you/they are unable.
- ○ Not work because of choice.

NEXT Screen Button here

Next Section

Next, we are going ask questions about your/your family member's rare disease(s).

How many rare diseases do you/they have?

- ○ 1
- ○ 2
- ○ More than 2

What is/are the name(s) of your/your family member's rare disease?

- ○ TEXT BOX HERE TO LIST RARE DISEAE(S)

On this screen we will have a link to the List of Rare Diseases | A-Z Database | NORD

Does the person with the rare disease seek healthcare in Nevada?

- ○ Yes
- ○ No (Please indicate where the person with the rare disease receives their healthcare)
  - ○ Drop down menu with choices to pick from

What State does the person with the rare disease live in?

- ○ Drop down menu with choices to pick from

NEXT Screen Button here

Next, we will ask questions about your/your family member’s rare disease(s)

How many rare diseases do you/your family members have?

○ 1
○ 2
○ More than 2

Have you/your family member received a confirmed diagnosis of this rare disease or condition by a doctor?

○ Yes, I/They have a confirmed diagnosis.
○ No, I/They have an unconfirmed diagnosis.
○ No, I/They do not have a diagnosis.

Select the statement below that best describes the time course of your/your family member’s rare disease(s) (meaning-depending on the disease(s), the expected time course may be years or decades or even months).

○ It is stable- not deteriorating or likely to progress.
○ It is progressive -worsening and is known to continue to worsen over time
○ It is episodic- characterized by the appearance of symptoms in discrete, often brief, periods or episodes.
○ It is improving.
○ Don’t know.

NEXT Screen Button here

Next Section

How long have you/your family member experienced symptoms of the rare disease(s)? If you have more than one rare disease, please respond about the first one you have or have known about the longest.

○ 0-6 months
○ 7-11 months
○ 1-3 years
○ 4-6 years

- ○ 7-9 years
- ○ 10+ years

How long after seeking medical help did it take for you/your family member to get a confirmed diagnosis? If you have more than one rare disease(s),

- ○ 0-6 months
- ○ 7-11 months
- ○ 1-3 years
- ○ 4-6 years
- ○ 7-9 years
- ○ 10+ years
- ○ Still undiagnosed

NEXT Screen Button here

Next Section

How many doctors have you/your family member seen to get a confirmed diagnosis? If you have more than one rare disease(s), please respond about the first one you have or have known about the longest.

- ○ 1
- ○ 2-3
- ○ 4-4
- ○ 6-10
- ○ 11-15
- ○ More than 15
- ○ Don't know.

If you/your family member have not received a confirmed diagnosis, how many doctors have seen so far in your attempt to get a diagnosis?

- ○ 1
- ○ 2-3
- ○ 4-4
- ○ 6-10
- ○ 11-15
- ○ More than 15

- ○ Don’t know.

NEXT Screen Button here

Next Section

How long ago was a conformed diagnosis made?

- ○ Less than a year ago. Please indicate how many months ago.
  - ○ TEXT BOX HERE
- ○ More than a year ago. Please indicate how many months ago.
  - ○ TEXT BOX HERE

Who diagnosed the person with the rare disease or condition? Select all that apply.

- ○ General Practitioner/Primary Care Provider
  - ○ Adult Provider
  - ○ Pediatric Provider
- ○ Allied health professional (e.g., optician (eye doctor) physical therapist, podiatrist, speech therapist, nutritionist, occupational therapist)
- ○ Local medical specialist (e.g., specialist doctor in Nevada) Please describe (e.g., geneticists, neurologist, allergist, hematologist)
  - ○ TEXT BOX HERE FOR DESCRIPTION
- ○ National medical specialist (e.g., specialist doctor outside of Nevada) Please describe (e.g., geneticists, neurologist, allergist, hematologist)
  - ○ TEXT BOX HERE FOR DESCRIPTION
- ○ Hospital emergency department
- ○ Dental services (e.g., dentist, dental hygienist)
- ○ Mental health services (e.g., psychiatrist, psychologist, counselor)
- ○ Alternative health service (e.g., acupuncturists, naturopath, homeopath, or any other alternative health service)
- ○ Other (Please describe)
  - ○ TEXT BOX TO DESCRIBE

NEXT Screen Button here

Next Section

Sometimes people with rare disease(s) experience situations related to the diagnosis, management or treatment of their rare disease that have felt difficult of frustrating. These are often called “barriers”. Reflecting on your own situation, please describe the most significant barrier you have experienced. Please be as specific as possible (If there are none, please note “none”)

- TEXT BOX TO DESCRIBE

Sometimes people with rare disease(s) experience situations related to the diagnosis, management or treatment of their rare disease that have positive or helpful. These are often called “facilitators”. Reflecting on your own situation, please describe the most helpful support you have experienced. Please be as specific as possible (If there are none, please note “none”)

- TEXT BOX TO DESCRIBE

NEXT Screen Button here

Next Section

How would you rate the experience with the doctor that you first reported your symptoms to?

	Poor	Fair	Neutral	Good	Excellent	N/A
Knowledge of rare disease(s)						
Willingness to ask other local doctors for help with diagnosis						
Willingness to ask regional/national doctors for help with diagnosis						
Willingness to do research to make a diagnosis						

Willingness to investigate symptoms to help with making a diagnosis						

NEXT Screen Button here

Next Section

How would you rate the experience with the doctor that first gave you a diagnosis of a rare disease(s)?

	Poor	Fair	Neutral	Good	Excellent	N/A
Knowledge of rare disease(s)						
Willingness to ask other local doctors for help with diagnosis						
Willingness to ask regional/national doctors for help with diagnosis						
Willingness to do research to make a diagnosis						
Willingness to investigate symptoms to help with making a diagnosis						

NEXT Screen Button here

Next section

Looking back at the time of your/their confirmed diagnosis, do you think you/your family member were given enough information on your/their rare disease(s) or condition?

- ○ Yes
- ○ No

Did you/your family member understand all of the information initially provided about your/their rare disease(s) or condition(s) at the time of diagnosis?

- ○ Yes
- ○ No

What other comments do you have about your/your family member being diagnosed with a rare disease(s) or condition? What information was helpful/unhelpful? Was there information that you wish you had received but didn't?

- TEXT BOX

NEXT Screen Button here

Next Section or Screen

Next, we are going to ask you about your/your family members health insurance.

What kind of health insurance or medical coverage does the person with the rare disease have? Select all that apply.

- Private insurance
- Healthcare marketplace/ exchange insurance
- Medicaid- regular fee for service
- Managed Medicaid
  - UnitedHealthcare/HPN
  - Silver Summit
  - Anthem
  - Molina
- Medicare
- Managed Medicare
- Medicare supplement
- Military related coverage including VA health care, Tri-Care/TriWest, and CHAMP-VA
- Other (please describe)
  - TEXT BOX
- The person with the rare disease does NOT have health insurance or medical coverage.

Does the person with the rare disease have the following coverage?

- Dental
- Vision

NEXT Screen Button here

What have you/your family member paid (approximately) in out-of-pocket expenses over the last calendar year for **health insurance or medical coverage** (please include your portion of any employer sponsored benefits).

○ $0-$499
○ $500-$999
○ $1,000-$1,499
○ $1,500-$1,999
○ $2,000-$2,999
○ $3,000-$4,999
○ Over $5,000
○ Over $10,000
○ Over$15,000

What have you/your family member paid (approximately) in out-of-pocket expenses over the last calendar year for **health care (doctor's office co-pays, deductibles', co-insurance, prescriptions, etc.)**

○ $0-$499
○ $500-$999
○ $1,000-$1,499
○ $1,500-$1,999
○ $2,000-$2,999
○ $3,000-$4,999
○ Over $5,000
○ Over $10,000

NEXT Screen Button here

Next Section

Have you/your family member ever been denied care or experienced a delayed in care of any of the following because pre-approval from a health insurance carrier was required?

	East to get	Delayed	Denied	N/A
Diagnostic Testing				
Home Care Services				
Specialty Laboratory Tests (e.g., genetic testing or bio-marker testing)				
Referral to Physical Therapy				
Referral to Occupational Therapy				
FDA Approved Medication				
Home Medical Equipment (e.g., oxygen, hospital beds, assist lifts, etc.)				
Durable Medical Equipment (e.g., walkers, wheelchairs, commodes, etc.)				
Investigational treatment				
Off Label Medication Use				

NEXT Screen Button here

Next Section or Screen

Have you/your family member’s insurance ever denied a referral to a medical or dental specialist?

○ Yes

○ No

Has your/your family member’s insurance ever denied you/them access to a medical or dental services or procedures because the rare disease you/they have does not have a defined “standard of care”?

○ Yes

○ No

Has your/your family member’s insurer ever denied you seeing a specialist in your rare disease due to that specialist being “Out of Network”?

○ Yes

○ No

NEXT Screen Button here

Next Section or Screen

Next, we have some questions about the information, support, and care that the person with the rare disease received regarding their diagnosis.

Have you/your family member had sufficient information and care for the rare disease from each of the following sources?

Sufficient Information:

	Strongly Dis-agree	Disagree	Neutral	Agree	Strongly Agree	N/A
General Practitioner/PCP						
Medical Specialist						
Allied Health Professionals (PT/OT)						
Dental Professional						

Patient Organizations						

NEXT Screen Button here

Next Section or Screen

Have you/your family member had sufficient information and care for the rare disease from each of the following sources?

Sufficient Care:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
General Practitioner/PCP						
Medical Specialist						
Allied Health Professionals (PT/OT)						
Dental Professional						
Patient Organizations						

NEXT Screen Button here

Next Section

How would you rate your/your family member's knowledge from 1 (no knowledge) to 10 (complete knowledge) on your/your family member's rare disease:

1	2	3	4	5	6	7	8	9	10

If you rated your knowledge as less than 10, specially, what information do you feel you are missing?

- ○ TEXT BOX

NEXT Screen Button here

Next Section or Screen

Do you agree or disagree that you/your family member received sufficient support in the following areas at the time of diagnosis?

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Medical Team (Doctors, Nurses)						
Dental Team						
Social (family, friends, church, etc.)						
Financial (Insurance Coverage)						
Mental Health Team						

NEXT Screen Button here

Next Section or Screen

Do you know if there is a specialist center for your/your family member's specific rare disease(s) or condition(s)?

- ○ Yes
- ○ No

Do you/your family member access a specialist center for your/their specific rare disease(s)?

- ○ Yes
- ○ No

If you/your family member does not access a specialist center, why not? (Select all that apply)

- ○ There is not one for my/their specific rare disease in the Nevada.
- ○ My insurance does not cover it.
- ○ I live too far and have no way to get there.
- ○ They are not accepting new patients.
- ○ The wait list is too long.
- ○ Other

TEXT BOX

NEXT Screen Button here

Next Section or Screen

How many different medical specialists (e.g., specialist doctors) do you/your family member see for your/their rare disease(s)

- ○ 1-2
- ○ 3-4
- ○ 5-6
- ○ More than 6

What is the furthest distance traveled for you/your family member to access care for the rare disease?

- ○ Less than 10 miles
- ○ 1-29 miles
- ○ 30-59 miles
- ○ 60 or more miles
- ○ Out of state
- ○ International

Do you use telehealth services to see medical specialists?

- ○ Yes
- ○ No
- ○ I do not have access to the technology required for telehealth.

Would you interest in telehealth e/health services?

- ○ Yes
- ○ No
- ○ I do not have access to the technology required for telehealth.

NEXT Screen Button here

Next Section or Screen

Do you/your family member have a designated care coordinator?

- ○ Yes
- ○ No

If you have used a care coordinator, rate on a scale from 1 to 10 how helpful it was, with 1 being not helpful at all to 10 being extremely helpful.

1	2	3	4	5	6	7	8	9	10

If you have used a care coordinator, what worked well and what did not?

- ○ TEXT BOX

If you have not used a care coordinator, why not?

- ○ TEXT BOX

NEXT Screen Button here

Next section or screen

Were you/your family member ever cared for by a pediatric center for your/their rare disease(s)?

- ○ Yes
- ○ No
- ○ Don't know.

If you/your family member has been treated at a pediatric center for rare diseases, rate your satisfaction on a scale from 1 to 10, with 1 being not satisfied at all to 10 being extremely satisfied.

1	2	3	4	5	6	7	8	9	10

Did you/your family member transition from pediatrics to adult health care services?

- ○ Yes
- ○ No
- ○ Not Yet

If transitioned, what was the timeframe between your/your family members last visit to a pediatric center and the first visit to an adult center?

- ○ TEXT BOX

Was the timeframe acceptable or unacceptable?

- ○ Acceptable
- ○ Unacceptable

Did you/your family member experience any problems in the transition from pediatrics to adult services?

- ○ Yes, please explain.
  - ○ TEXT BOX
- ○ No

NEXT Screen Button here

Next Section or Screen

How would you compare the knowledge and expertise of rare disease(s) of your/your family member's pediatric provider to your/your family member's adult provider?

- ○ They have similar expertise and knowledge regarding rare diseases(s)
- ○ The pediatric provider has more expertise and knowledge than the adult provider.
- ○ The adult provider has more expertise and knowledge than the pediatric provider.

Were you/your family member given any information about possible research specific to your rare disease(s)?

- ○ Yes
- ○ No

Do/does you/your family member participate in any clinical research?

- ○ Yes

- ○ No

NEXT Screen Button here

Next Section or Screen

If the person with the rare disease is a child now or was a child when diagnosed, was the school prepared to take care the person with the rare disease while they attended school?

- ○ Yes
- ○ No
- ○ N/A

Does/did the person with the rare disease require any special accommodations while at school?

- ○ Yes
- ○ No
- ○ N/A

Does/did the person with the rare disease take medication while at school?

- ○ Yes
- ○ No
- ○ N/A

Did the person with the rare disease(s) school ask the healthcare team for education regarding their rare disease?

- ○ Yes
- ○ No
- ○ N/A

NEXT Screen Button here

Next Section or Screen

For clarity of the survey-

- ○ A 504 Accommodation Plan is put into place to ensure that a student with a disability has access to accommodations that improve academic functioning. The program is guided by the Americans with Disabilities Act (ADA).
- ○ IEP is an Individualized Education Plan This is a plan or program developed to ensure that a child with an identified disability who is attending an elementary or secondary educational institution receives specialized instruction and related services. The IEP is developed by a team of individuals from various educational disciplines, the child with a disability, family members, and/or designated advocates.

NEXT Screen Button here

Next Section or Screen

Does/did the person with the rare disease(s) have a 504 Accommodation Plan or IEP?

- ○ Yes
  - ○ 504 Plan
  - ○ IEP
- ○ No
- ○ N/A

Was the person with the rare disease offered a 504 or IEP?

- ○ Yes
  - ○ 504 Plan
  - ○ IEP
- ○ No
- ○ N/A

How long did I take to get the 504 and/or IEP in place?

- ○ 1-3 months
- ○ 4-9 months
- ○ 10-1 year
- ○ Over 1 year

How successful is/was the 504 Plan and/or the IEP?

- ○ 504
  - ○ TEXT BOX
- ○ IEP

- ○ TEXT BOX

NEXT Screen Button here

Next Section or Screen

Next, we have some questions about the challenges you/your family member may have had getting care or treatment for the are disease(s).

Did any of the following limit you/your family member's ability to get medical or dental care or treatment for your/their rare disease?

	Never	Sometimes	Most of the time	Almost always	Don't Know
Finances					
Travel Distance					
Difficulty getting off work					
Lack of/delay in referrals					
Not covered by insurance					
Other					

Have you/your family member needed to relocate in order to access treatment or clinical trials for your/their rare disease?

	No	Temporarily	Permanently
In-State			
Out of State			

If you/your family member relocated because of a rare disease, please describe why:

- ○ TEXT BOX

NEXT Screen Button here

Next Section or Screen

Please think about your overall experience with the healthcare you received for you/your family member's rare disease(s) when responding to the following statements.

If you are a caregiver, please answer the following questions in terms of how the person with the rare disease(s) is feeling. If the person with the rare disease is under the age of 10, please answer based on your experience with them as a caregiver.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Healthcare providers are good about explaining the reason for medical tests.						
I think my healthcare providers office has everything needed to provide complete medical care						
The medical care I have been receiving is high quality						
Sometimes healthcare providers make me wonder if their diagnosis is correct						
I feel confident that I can get the medical care I need without being set back financially.						
When I go for medical care, they are careful to check everything when treating and examining me						
I must pay for more of my medical care than I can afford						
I have easy access to the medical specialist I need						
Where I get medical care, I have to wait too long for emergency treatment						

NEXT Screen Button here

Next Section or Screen

Please think about your overall experience with the healthcare you received for you/your family member's rare disease(s) when responding to the following statements.

If you are a caregiver, please answer the following questions in terms of how the person with the rare disease(s) is feeling. If the person with the rare disease is under the age of 10, please answer based on your experience with them as a caregiver.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Healthcare providers act too business like and impersonal						
My healthcare team treats me in a very courteous and friendly manner						
Those who provide medical care sometimes hurry too much when they treat me						
Healthcare providers sometime ignore what I tell them						
I have some doubts about the ability of the healthcare providers who treat me						
I find it hard to get an appointment for medical care right away						
I am dissatisfied with some things about the medical care I receive						
I can get medical care whenever I need it						

NEXT Screen Button here

End with a Thank you message.