



# Rare Disease Advisory Council

STATE OF UTAH  
Disease Control and Prevention

To: Health and Human Services  
From: Kim, Hart, Division of Disease Control and Prevention  
Subject: Statutorily Required Report for 26-1-41  
Date: add the date here: 11/30/21?

## Executive Summary

During the 2020 session, the Utah Legislature passed HB106, establishing the Rare Disease Advisory Council (RDAC) within the Utah State Department of Health (UDOH). The bill was sponsored by Rep. Lee Perry and Senator Luz Escamilla. The motivation for the bill was a constituent family of Rep. Perry coping with a rare disease. The term Rare Disease references a malady that affects fewer than 200,000 people in the United States. The needs of these patients are unique and require special attention. The trend of establishing councils like this is growing and Utah is among the first states to establish such a council designed to better address the needs of rare disease patients and caregivers.

Due to COVID-19, the Utah Legislature in June of 2020 reversed some new appropriations granted in the 2020 general session, including the \$9500 appropriated to the UDOH for establishing the RDAC. This funding was restored by in the 2021 legislative session and included in the appropriations for fiscal year 2022 and beyond as an on-going appropriation. The restoration of this funding allowed the UDOH to begin the process of forming the RDAC.

Following the provisions of HB106, the UDOH has appointed a Grantee to manage and administer the RDAC. The Grantee selected was BioUtah, the state trade association for life sciences companies. Working with BioUtah, the UDOH solicited applications for the RDAC. In September 2021, those applications were reviewed and members of the RDAC were selected. The first meeting of the RDAC was scheduled for November 19, 2021.

HB106 requires a report be submitted by November 30, 2021 and by November 30 of every odd numbered year thereafter. This report is responsive to that requirement.

## Findings/Primary Report

Due to the delayed funding caused by the COVID-19 pandemic, there is not the expected 18 months of activity to report that was originally anticipated when the original bill was passed. The one year delay in funding has left approximately five months of activity to report.

Knowing funding would be available in FY22, the UDOH began the process of selecting a Grantee as required in the Statute. In April & May, UDOH solicited Grantee applications. During the month of June those applications were evaluated and in the first week of July, BioUtah was selected as the Grantee. The contract calls for a singular payment of \$9500 to BioUtah in June of each year to cover the prior 12 month period.

The contract with BioUtah was negotiated during the month of July and ultimately signed in late August, 2021. During that same period of time, UDOH worked closely with BioUtah to solicit applications for membership on the RDAC in July and August. The applicants were evaluated during the month of September and members selected according to requirements in the statute and notified in October 2021. The first meeting was scheduled for November 19, 2021.

Members selected for the RDAC are included at the end of this report.

In addition, UDOH has launched a website, [www.health.utah.org/RDAC](http://www.health.utah.org/RDAC), that provides basic information and will be a tool for furthering the work of the RDAC. Grantee, BioUtah, is preparing By-Laws for UDOH to review that will be applicable to the RDAC.

On November 19, 2021, the RDAC held its first meeting. The agenda and minutes from the first meeting are included below. Meeting outcomes included:

- Members of the RDAC becoming acquainted and sharing their perspectives about what the RDAC Mission should be.
- By Laws were reviewed and adopted
- Training provided by National Organization for Rare Disorders (NORD)
- Decision made to meet every 2 months which exceeds the minimum 2 meeting per year required in statute.
- Add additional information as the Council meeting dictates.

The next meeting of the RDAC is scheduled for January 24, 2022.

Attached below:

RDAC membership

Meeting Agenda

Meeting Minutes

## UTAH RARE DISEASE ADVISORY COUNCIL (RDAC) MEMBERS

### **Sachin Apte, MD**

Physician-in-Chief, Chief Clinical Officer  
Huntsman Cancer Institute at the University of Utah

### **Lorenzo D. Botto, MD (RDAC CHAIR)**

Professor of Pediatrics, Division of Medical Genetics  
University of Utah and Primary Children's Hospital

### **Marian Furst**

Patient with rare disorder

### **Kim Hart, MS CGC**

Newborn Screening Program, Utah Department of Health

### **Marimee (Toya) Jules (RDAC Secretary)**

Patient with rare disorder

### **Sylvia Lam**

Executive Director, United Angels Foundation  
Advocacy group

### **Heidi Maxfield**

Board Director, Intermountain PKU & Allied Disorders  
Advocacy group and parent of child with a rare disorder

### **Kristen Pauley, MS CGC**

Genetic Counselor, Huntsman Cancer Institute

### **Matthew Pearl**

Utah Volunteer State Ambassador, RareUT.org  
<https://rareaction.org/resources-for-advocates/state-profiles/utah/>

### **Gina Szajduk (RDAC Vice Chair)**

Co-founder and Executive Director, Rare and Undiagnosed Network (RUN)  
Parent of children with an undiagnosed rare disorder

### **Pinar Bayrak-Toydemir, MD, PhD, FACMG**

Professor, Department of Pathology, University of Utah  
Medical Director, Molecular Genetics and Genomics, ARUP Laboratories

### **Melodie Weller, PhD**

Assistant Professor  
School of Dentistry, University of Utah

### **Dave Viskochil, MD PhD**

Professor of Pediatrics, Division of Medical Genetics  
University of Utah and Primary Children's Hospital

### **BioUtah Administrators**

#### **Kelvyn Cullimore**

President and CEO  
BioUtah

#### **Denise Bell**

Vice President, Programming and Government Affairs  
BioUtah

## AGENDA

### MEETING OF THE UTAH RARE DISEASE ADVISORY COUNCIL (RDAC)

**Date:** Friday, November 19, 2021

**Time:** 1:00 - 3:00 PM MT

**Location:** Virtual (Zoom)

**Zoom Link:** <https://us02web.zoom.us/j/86952714161>

---

- I. Call to Order (Dr. Lorenzo Botto)**
  - A. Chair's remarks
  
- II. Welcome and Introductions (Dr. Lorenzo Botto)**
  - A. Introductions of council members/administrators
  
- III. Council Selection and Appointment of Vice-Chair (Dr. Lorenzo Botto)**
  
- IV. Review the RDAC Statute - (Kim Hart)**
  - A. Role of Utah Department of Health and BioUtah
  - B. RDAC statute - responsibilities and deadlines
  
- V. Discuss, Review and Approval of By-Laws - (Kelvyn Cullimore)**
  
- VI. Guest Speaker: Overview of Rare Disease and RDACs - Alyss Patel, State Policy Manager for the Western Region at the National Organization for Rare Disorders (NORD).**
  
- VII. Discussion Items - (Dr. Lorenzo Botto)**
  - A. Concept of a survey
  - B. RDAC scope, priorities, mission statement and work plan
  - C. Concept of rare disease coalition
  
- VIII. Operational Issues - (Dr. Lorenzo Botto and Kelvyn Cullimore)**
  - A. Frequency of meetings
  - B. Website
  - C. Communication modes
  - D. Work streams (use of committees)
  - E. Non-voting members (standing and non-standing; liaison; ad hoc)
  
- IX. Future Meetings (Kelvyn)**

## **DRAFT - MINUTES OF UTAH RARE DISEASE ADVISORY COUNCIL**

**MEETING:** Utah Rare Disease Advisory Council (RDAC)

**DATE/TIME:** November 19, 2021  
1:00 pm - 3:00 pm MT

**LOCATION:** Virtual Meeting  
230 E S Temple, Salt Lake City, UT 84111

**CHAIRPERSON:** Dr. Lorenzo Botto

**IN ATTENDANCE** Dr. Lorenzo Botto  
Marian Furst  
Kim Hart  
Marimee (Toya) Jules  
Sylvia Lam  
Heidi Maxfield  
Kristen Pauley  
Matthew Pearl  
Gina Szajnuik  
Melodie Weller  
Dr. Dave Viskochil

**BioUtah Staff**

Kelvyn Cullimore  
Denise Bell

**Guests**

Janae Duncan, Utah Department of Health  
Marie Nagata, Utah Department of Health

**Excused Absence**

Dr. Sachin Apte  
Pinar Bayrak-Toydemir

### **CALL TO ORDER**

Chair, Dr. Lorenzo Botto called the meeting to order at 1:05 pm.

### **WELCOME AND INTRODUCTIONS OF RDAC MEMBERS**

At the request of Dr. Botto, each member of the council in attendance introduced themselves and shared their backgrounds with respect to rare disease.

Dr. Botto provided an overview of the agenda and offered thoughts on the scope of the council. He noted that this first meeting should acquaint members with each other and help council members understand the role of the Utah Department of Health (DOH) and basic rules of operation, as well as outline a process for the council to identify elements of a work plan and the needs of the Utah rare disease community.

## **REVIEW OF THE RDAC STATUTE**

Kim Hart (DOH) reviewed details of the state legislation that established the RDAC, including the role of the department and the role of the grantee (BioUtah) regarding the council's function. BioUtah, as grantee, is responsible for administrative support of the RDAC.

Hart further explained that the first report of the council is due November 30 and would primarily cover the following: grant award; appointment of council members and; first meeting.

In response to Dr. Botto's question about the DOH's work regarding rare disease, Kim and DOH colleagues indicated that the DOH's functions are largely focused on public health and noted that the issue of rare disease has to date been focused on newborn screening. It was further noted that the council would be important in informing the DOH on rare disease issues and serving as a voice for creating and directing DOH resources to rare disease, including bringing policy priorities to the state legislature.

The primary role of the RDAC is to advise the DOH and the state legislature on matters pertaining to rare diseases as outlined in the statute and in the by-laws.

**Action: For the next meeting, Dr. Botto asks the DOH to develop a list of programs, activities and resources within the DOH that would relate to the work of the RDAC.**

## **REVIEW OF PROPOSED BYLAWS**

Kelvyn Cullimore presented draft bylaws to the council and in particular, reviewed bylaw items related to council officers - Chair, Vice Chair and Secretary. Terms of appointments were also presented.

The council chair will serve two years. The vice chair will ascend to chair after two years. This could be problematic with a six year cycle, so a provision was added that any person serving as chair or vice chair is exempt from the six year limitation so they can complete their term.

Other council members will initially serve staggered terms of two or three years. Terms for each member were determined by a drawing conducted by BioUtah staff after the meeting. The term results are listed in the next section. Under the draft bylaws, members can be reappointed twice for a total of six years (or seven for those with an initial term of three years).

An amendment to the bylaws was proposed and approved that would require the approval of the DOH representative and a majority of the council to amend the bylaws.

In terms of voting, Cullimore noted that no proxy (surrogate) voting would be permitted.

**Action: Council was asked to share feedback on the draft bylaws by December 15. BioUtah will present an updated draft of the bylaws for review and approval at the next meeting. An updated draft of the bylaws reflecting the decisions in today's meeting will be sent with the minutes of the meeting.**

## **INITIAL TERMS FOR COUNCIL MEMBERS**

Dr. Sachin Apte	Two years	Heidi Maxfield	Two years
Dr. Lorenzo Botto	Three years	Kristen Pauley	Three years
Kira Chaney	Two years	Matthew Pearl	Three years
Marian Furst	Two years	Gina SzajnuK	Two years
Kim Hart	DOH representative	Dr. Pinar Toydemir	Two years
Toya Jules	Three years	Melodie Weller	Three years
Sylvia Lam	Three years	Dr. Dave Viskochil	Three years

## **APPLICATION OF OPEN MEETING LAW**

Hart noted that conversations are on-going with the department's attorney general as to whether Utah's Open Meeting law applies to the RDAC.

**Action: Hart will follow-up and provide a final determination to the council.**

## **SELECTION OF VICE-CHAIR AND SECRETARY**

Cullimore noted that two members of the council expressed interest in being considered for the position of vice-chair, Marimee (Toya) Jules and Gina SzajnuK. Both are rare disease patients, and Gina is a mother of three rare disease patients.

Both candidates briefly addressed the council and a vote was taken via text to Kim Hart, Utah Department of Health. Gina was selected as vice-chair. Toya accepted the position of Secretary.

## **GUEST SPEAKER**

Alyss Patel, state policy manager for the western region with the National Organization for Rare Disorders (NORD) addressed the council, providing an overview of rare disease and resources available to state RDACs, including surveys for the rare disease community. She briefed the council on the NORD report card for the state of Utah which rates the state on key issues affecting individuals living with rare disease. The report identifies areas in which Utah has made progress as well as areas that require more focus.

## **OPERATIONAL ISSUES**

### **• Frequency of meetings**

The council determined that for the first year, meetings would be held bi-monthly on the last Monday of each odd-numbered month, from 1:00 pm - 3:00 pm MT, with the possible exception of July, which the council may take off as a summer break.

**Action: Meeting notices will be posted on the RDAC website. Minutes will be sent to council members and minutes will be posted to the RDAC website. Meetings will remain virtual unless otherwise specified. BioUtah will send out calendar invites for 2022 meetings.**

### **• Website**

The website was viewed with the council.

**Action: The council requested that the website be more visible on the department website.**

• **Communication modes**

Dr. Botto reviewed the various means by which the council would do business. This includes emails, zoom calls etc between meetings to advance the work plan.

• **Work streams (use of working groups)**

Dr. Botto informed the council that working groups of the council could be formed to help facilitate the work plan.

• **Non-voting members**

Dr. Botto outlined for the council the option of adding non-voting members to the council, such as industry representatives and asked the council to contemplate recommendations. The council responded favorably in terms of considering additions.

Dr. Viskochil suggested appointing a council liaison to other state RDACs, which was also well-received by the council.

**DISCUSSION ITEMS/WORK PLAN**

Dr. Botto engaged the council in a preliminary discussion around developing the scope and short-terms goals of the council. The concept of a survey was proposed as a way in which to discern the challenges and needs of Utah's rare disease community. In addition, he expressed interest in having the council establish a mission statement. He shared work planning documents, such as the fishbone challenge, which the council will use to help define the council's initial goals, priorities and projects.

**Action: The work planning documents will be sent to each council member with a deadline of January 15 for completion. Council members will send their documents to Denise Bell at BioUtah. Dr. Botto also requested that the council provide ideas for agenda items for the January meeting. It was suggested that a guest speaker be featured.**

**FUTURE RDAC MEETINGS**

January 24, 2022

March 28, 2022

May 23, 2022

July 25, 2022 (TBD)

September 26, 2022

November 28, 2022

**ADJOURNMENT**

The chair adjourned the meeting of the RDAC at 3:00 pm MT.