

Rare Disease Advisory Council
Organizational Meeting Minutes 9/23/19

Present: Rep. Marsh, Rep Osborne, Sen. Rosenwald, Dr. Sai Cherala, Dr. Angela Shepard, Dr. Mary Beth-Dinulos, Krista Gilbert, Dr. Laura Landerman-Garber, Robert Stoker
Absent: Dr. Richard LaFleau, Dr. Elijah Stommel

Rep. Marsh called the meeting to order at 3pm.

Members present introduced themselves and their connection to the Rare Disease Community.
Rep. Polly Campion spoke on behalf of Dr. Elijah Stommel.
Paula Rogers spoke on behalf of Dr. Richard LaFleau.

Rep. Marsh reviewed the vision for Rare Disease Advisory Councils from NORD (National Organization for Rare Disorders) <https://rarediseases.org/> and the statutory charge to the Council (RSA 126-A:79 VI.

Sen. Rosenwald nominated Rep. Marsh as chair. Second by Rep. Osborne. There were no other nominations, and motion passed unanimously.

Discussion ensued regarding when and how frequently to schedule regular meetings.
Consensus was to meet Friday Oct 18 at 3pm at DHHS on Hazen Drive so that absent members could call into the meeting with decision to be made at that time whether to meet monthly or bimonthly.

The remainder of the meeting consisted of brainstorming how to address the goals of this council.

Meeting adjourned at 3:50pm

Respectfully submitted, Rep. Marsh Chair