

**Chairperson**  
Robert Bureau

**Members**  
James Delage (A)  
John Finn  
Dee Karuna  
Kate McGrath (A)  
Joseph Prochilo  
Stephen Stolberg

**Vice Chairperson**  
Elizabeth Myska



**City of Worcester**  
**Accessibility Advisory Commission**  
Tuesday, October 15, 2024, 4:30pm  
Worcester City Hall  
455 Main Street, Worcester, MA

### **Virtual Meeting with ASL interpreters**

THIS IS A VIRTUAL MEETING VOTING SHALL BE RECORDED BY ROLL CALL VOTE OF MEMBERS  
PRESENT

Members present: Chair Robert Bureau, Associate James Delage, Darya Karuna, Associate Kate McGrath, Elizabeth Myska, Joseph Prochilo, Stephen Stolberg (arrived 4:37)

Members absent: John Finn, Jr.

Staff present: Human Rights and Accessibility Director, Patricia M. LaFore, Esq., and Coordinator of Disability Rights Projects, Dawn E. Clark

Guests: Rachael Lee, MA Department of Conservation and Recreation

#### **1. Call to order, instructions for virtual meeting, introductions**

Chair Bureau requested P. LaFore provide the technology instructions for public access to the meeting. A roll call was taken to start the meeting at 4:33pm. The following answered present; Robert Bureau, Darya Karuna, Kate McGrath, Elizabeth Myska, Joseph Prochilo, Steve Stolberg

#### **2. Approval of September 17, 2024 minutes-**

Comm. Prochilo made a motion approve.

Comm. Bureau seconded the motion.

Roll Call Vote/yes/unanimous

#### **3. Dysautonomia Presentation (Associate Comm. McGrath) and discussion/questions by AAC members**

Associate Comm. Kate McGrath shared her personal story living with Dysautonomia as an active student and athlete. When she was 31 years old this

condition was finally diagnosed after years being misdiagnosed due to lack of awareness by even the medical professionals. There are no medications for this condition but there are medications for various symptoms. This condition affects more woman than men and tends to affect athletes after concussions.

October is Dysautonomia Awareness Month. The official color is turquoise. There is a need for more awareness, knowledge and funding for research.

Dysautonomia, also known as Dys, is a medical condition in which a person does not have full function of the autonomic nervous system that controls every function of the body that happens “automatically”. The autonomic nervous system controls all organs, muscles, tissues, tendons, nerves, and more. Dysautonomia affects the entire body.

POTS (Postural Tachycardia Syndrome) is one of the fifteen types of Dys. A person with POTS cannot regulate heart rate and blood pressure, especially when they change position from sitting to standing. For example, the heart rate increases while the blood pressure dramatically decreases, and they have presyncope, which is the feeling right before you fully pass out, and sometimes, people fully pass out.

Misdiagnosis required many years going to doctors and many surgeries. Stories like this are coming out through social media and other ways verifying the medical world is not aware of this condition. There are less than 100 doctors in the world that specialize in Dysautonomia. There is just a handful of Fellowship’s to study the condition. There is a lack of awareness and research funding for this the annual budget of the National Health Institute’s \$47 million: 1% is used for Dysautonomia research.

Associate Comm. McGrath started an informal campaign called “Diss the Dys” which means Dissolve the Dysautonomia with the goal of making awareness of this condition known so that more treatment options are available.

What is being done locally for achieving awareness:

1. The Bridge between Worcester and Shrewsbury is it up in turquoise for Dysautonomia Month.
2. The Blackstone Footbridge over Rt.146 is in turquoise as well.
3. In April 2024 there was a pre-game awareness event at the WooSox.
4. Assoc. Comm. McGrath would like the AAC to request the mayor to sign a proclamation to recognize October as Dysautonomia Awareness Month.

Questions and further discussion:

Is there a connection between athletes and Dysautonomia?

McGrath – Yes, the connection is believed to result in people who have sustained concussions.

Is there an effort for medical schools around the world to train future medical personal about Dysautonomia?

McGrath – Yes, there are two Non-profits – The Dysautonomia Project and Dysautonomia International

Is this a rare condition and what percentage of the population does it effect?

McGrath – Dysautonomia is not considered a rare condition, and it affects 70 million people around the world.

Several Commissioners thanked Ms. McGrath for being vulnerable and sharing her story and asked if there was something they could do to help bring awareness. McGrath indicated having the AAC support a request to the mayor for a proclamation and recommendations for other places to provide turquoise lighting associated with the condition.

Commissioner Karuna made a motion for the Commission to request the mayor to proclaim October 2024 Dysautonomia Awareness Month.

Vice Chair Myska seconded the motion.

A roll call was taken and unanimously approved.

4. **MA Dept. Conservation & Recreation (DCR)– Universal Access Program with Rachael Lee**

Ms. Lee presented a series slides focused on Worcester area parks DCR oversees public parks across Massachusetts. The mission is to protect, promote and enhance the State's natural, cultural and recreational resources. In 1995 Universal Access Program (UAP) was started and provides outdoor recreation opportunities in Massachusetts state parks, forests, pools and rinks for visitors of all abilities.

Site improvements – Making sure buildings and trails are accessible so people can recreate independently.

Adaptive recreation equipment - beach wheelchairs and other equipment is provided.

Adaptive recreational programs & events like boating/canoeing, kayaking, hiking, golf, and swimming across the state – spring, summer and fall. In the winter, in and outdoor skating, cross country skiing and sledding.

There are 5 full time employees at the Universal Access Program. Contracted vendors provide most of the programing. Locally, Easter Seals provided a swimming program at Bennet Pool. There was a paddling program at Quinsiquamond Lake. There was a picture with Comm. Myska from 2016. Every year the ADA Day is celebrated at Dunn State Park.

Rachel Lee urged people to stay in touch

- Visit [mass.gov/dcr/access](https://mass.gov/dcr/access)
- Sign up for mailing list: [DCR.UniversalAccess](mailto:DCR.UniversalAccess)
- Get on DCR public meeting list: [mass.parks@mass.gov](mailto:mass.parks@mass.gov)

Questions and discussion:

Are there programs with animals?

Ms. Lee: Prior to the pandemic, there was a horseback riding program. The vendor decided not to renew. Bringing animals to parks was a lot of work. DCR depends on vendors to provide programing. She then asked if the Comm. had a suggestion. Grafton Animal Hospital was suggested. She asked that contact information be sent to her.

Vice Chair Myska who was in one of the photos shown gave some personal comments.

Does DCR have any plans to have a sled hockey team?

Ms. Lee: Possibly with a partner agency/group All equipment needs to stay on State property. DCR was working with Spaulding on State land. If there are others who would like to be vendors, DCR would be happy to consider a sled hockey team/program.

Comm. Stolberg said that he participated in the hand cycling program, but because it is so far away, he has not been able to participate in a while. He registered for a couple of local ones, but they were canceled due to the weather. Ms. Lee: DCR is hoping to expand that program. We conduct more programs in the spring and fall in recognition of the summer getting hotter which reduces participation.

Director LaFore thanked Rachael and said she had a friend whose child has been involved with DCR sled hockey in the Springfield area for many years. So, this was an interest of hers as well.

Ms. Lee: She put her contact information in the chat and asked that people be in touch. Maybe a sled hockey team or a sports alliance could be developed in Worcester.

5. **AAC Elections- this is a holdover item that shall be carried on the agenda for several months going forward**

No action taken.

6. **Announcement: Today is 2024 White Cane Day-discussion or comments by event participants**

This is the 60<sup>th</sup> Anniversary of the passage of legislation naming White Cane Day. Vice Chair Myska organized the 10<sup>th</sup> Worcester White Cane Walk with eight MA Dept. of Transportation engineers. They meet at UMass University School and traversed Plantation Street to Shrewsbury Street and back for a debrief. They were blindfolded and used a white cane assisted by sighted guides. The purpose was to give the experience of being blind so there would be awareness of issues related to uneven sidewalks and crossing busy streets etc.

Participant Jessica, mother of a blind child who is learning to use a white cane and used a braille reader, spoke about her experience and her takeaways:

- Gripped the sighted guide's arm a little tighter when she heard a noise or hit something with her foot.

- Sighted guide helped her confidence by explaining the environment around them
- Frightening to cross six lanes of traffic even with a sighted guide. Her hearing was more pronounced.
- Did not hear talking signals. The button to push for crossing streets were hard to find and not always in the sane place on the pole.
- If she did not have a sighted guide and was blind, she would want to wait for quiet and then she would be uncomfortable to cross.
- Some traffic islands do not have cross signals.
- The alignment of the crosswalks was not always straight across. With the stroller holding her younger daughter and the sighted guide, the wheelchair would get stuck on uneven ground and hard to switch direction to get across street.
- She referred to her daughter's experience when she comes to a dip in the surface her cane would hit her in the stomach which is painful.
- Some of the sidewalks were wide so two could walk side by side.
- 

Another noteworthy observation was that employees were bused from the parking lot to cross the large road into the hospital, yet the public was required to cross a road without transportation or assistance. She suggested that kids and their parents should have this opportunity. Their skills may be very insightful!

Questions and discussion:

How can we help?

Vice Chair Myska said Congressman McGovern was also among the participants this morning and asked this same question. She was listening to a program saying autos were getting bigger and more dangerous for pedestrians especially children.

We need to find a way we all can safely share the streets/sidewalks. Keeping this in mind, we may be able with the city to develop a program going forward.

How expensive are the signals?

Vice Chair Myska has been working with the engineers since August and learned the issue is more related to practices. Some signals sound like birds and some like human voices which is a problem due to being inconsistent thus unreliable. VIPs are trying to figure out what they are hearing rather than using the time to cross

the street. The engineers are interested in working with a group like the VIPs.

Perhaps the AAC could advocate for an accessible walk audit as opposed to a walk audit.

7. **Planning Discussion for 35<sup>th</sup> ADA Anniversary**

Vice Chair Myska suggested because the 35<sup>th</sup> ADA Anniversary falls on a Saturday this summer there may be more opportunity for people to attend. In 2025, the 25<sup>th</sup> ADA was celebrated in Union Station. Many agencies work to make this event successful with exhibitors, entertainers, decoration, food, etc.

The Commission wanted to think about this and revisit the issue in November.

8. **Review of AAB notices and applications –  
Decision**

- 1 Gage Street

No action taken.

9. **Update on hiring process for Chief Equity Officer, EODEI and HR&A Program Coordinators**

The Chief Equity Officer has been hired and will begin on October 28<sup>th</sup>. His name is Kevin Lovaincy.

On Monday, interviews for the EODEI Program Coordinator will take place and applicants for the HR&A Coordinator have been scored and hopefully ready for next week to interview.

10. **Suggestions for future agenda items-**

2024 – 2025 Snow removal plans

Follow-up on the ADA/Disability Pride Celebration this summer

Follow up on elections

11. **Announcements**

- **Next Accessibility Advisory Commission meeting: Tuesday, November 19, 2024.**

**\*WRTA Transportation Advisory Planning Group – Wednesday,  
October 23, 2024 - 1 -2:30pm**

**\*Emergency Preparedness Tip: Click here for a list of items and other  
helpful tips: <https://www.ready.gov/>**

**Adjournment:**

Comm. Prochilo made a motion to adjourn @ 6:34 pm

Comm. Bureau seconded the motion.

Roll Call Vote/all/yes/unanimous.

**Items relied upon for this meeting-**

-Agenda

-Dysautonomia Presentation

-MA Dept. of Conservation & Recreation – Universal Access Program Presentation