Solve M.E.

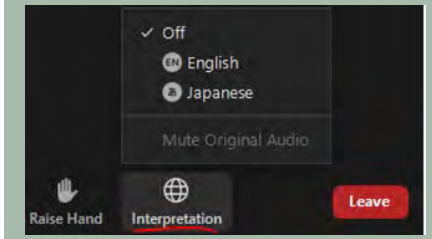
VIRTUAL

ADVOCACY MONTH

MAY 2022

About Our Webinars

Español:



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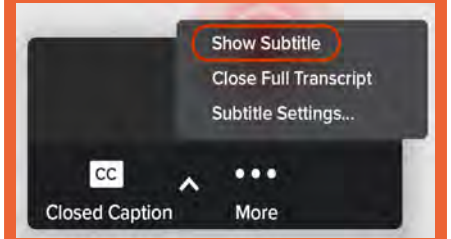

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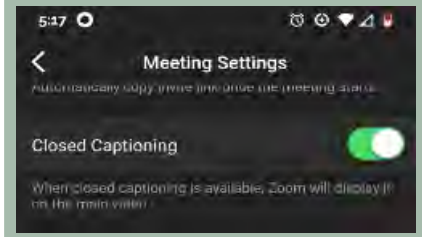

- Webinars are recorded and will be available on our YouTube channel: http://youtube.com/SolveCFS
- Solve M.E. does not provide medical advice
  - We are not endorsing the presenter or the content of the presentation
  - Consult your doctor — do not use experimental or non-FDA approved treatments without medical supervision

Online Schedules and Logistics Overview

From: Advocacy Day <advocacyday@advocacyassociates.com>
Sent: Tuesday, [illegible]
To: Caroline Smith <carolinesmith1547302@gmail.com>
Subject: Schedule for ZLA Virtual Hill Day 2022

Hello Caroline Smith,

You can view your schedule for ZLA Virtual Hill Day 2022 here: https://zla.constituentvoice.net

To access your meeting schedule, click on the link above and log in with the following credentials:

Username: carolinesmith1547302@gmail.com

Password: pwB9YH7!

PLEASE NOTE: This is a temporary password. After logging in, you will be prompted to create a new password. Once you've created a password, you will be logged into your portal automatically.

If you forget your password, you can go to zla.constituentvoice.net and click the "Forgot Password" button to reset your password.

If you have any questions or concerns, please contact support here:
zla.constituentvoice.net/contact

Thank you,
Advocacy Associates

Receiving Your Schedule

- You will receive an automated email from Advocacy Associates on **May 3rd**
- Check your SPAM/JUNK folder if you think you did not receive the email
  - Verify with your organization on the date schedules were/will be sent
- Didn't receive or can't find in your spam/junk folder? Go to:

solvemecfs.constituentvoice.net/contact

From: Advocacy Day <advocacyday@advocacyassociates.com>
Sent: Tuesday, January 11, 2022 7:31 AM
To: Caroline Smith <carolinesmith1547302@gmail.com>
Subject: Schedule for ZLA Virtual Hill Day 2022

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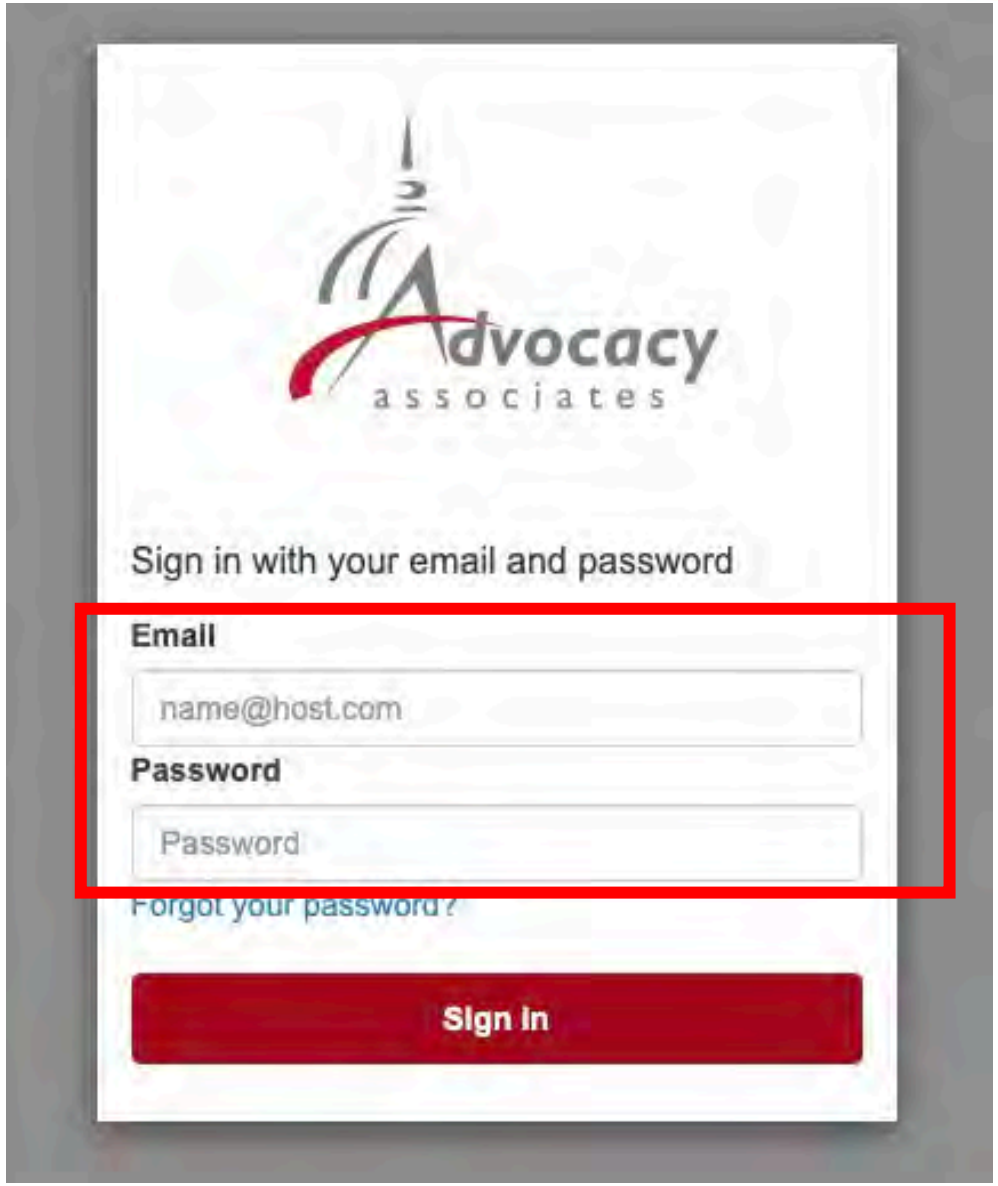
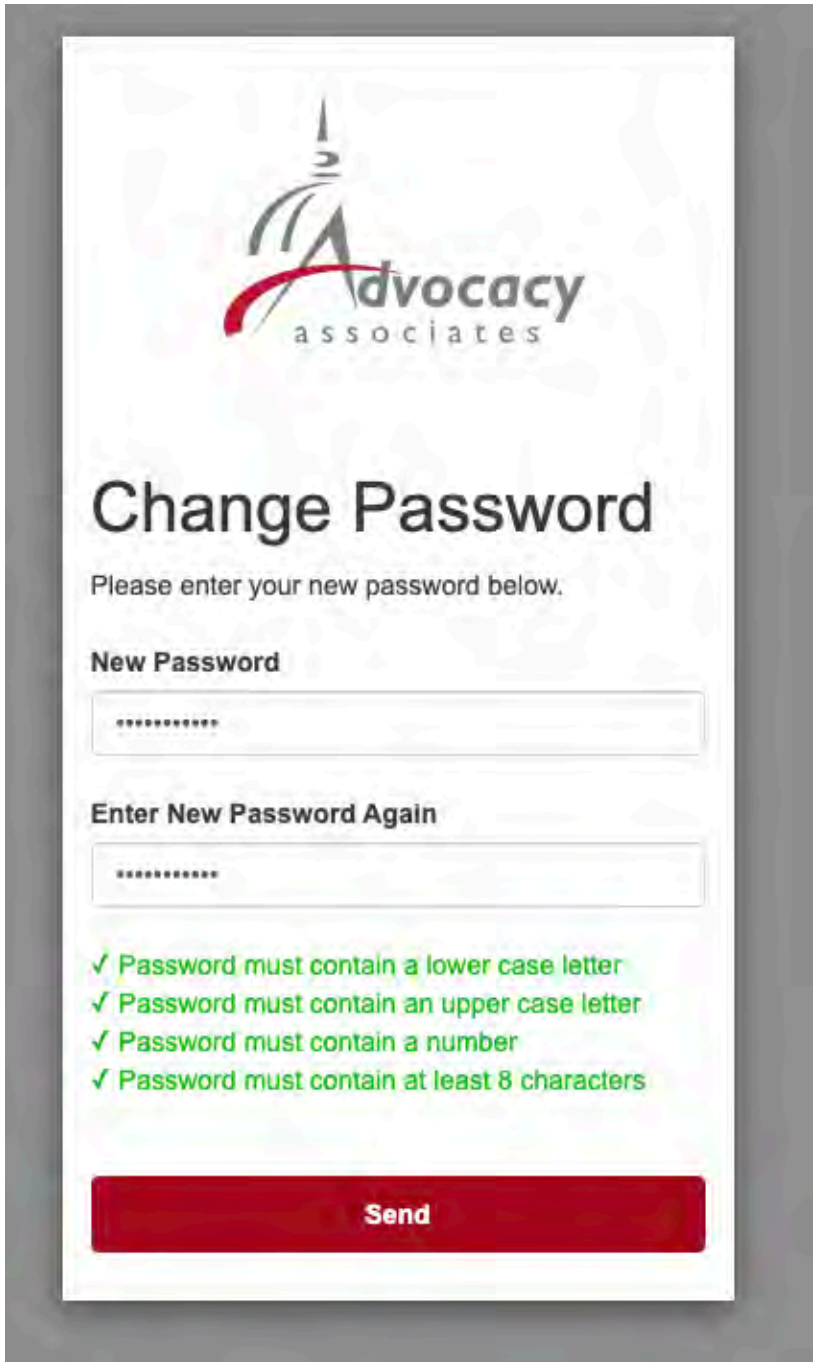
  - Verify with your organization on the date schedules were/will be sent
- Click on the URL to access your schedule. You will need your login credentials



Accessing Your Schedule

- Enter your email and temporary password that was provided in your initial email



Accessing Your Schedule

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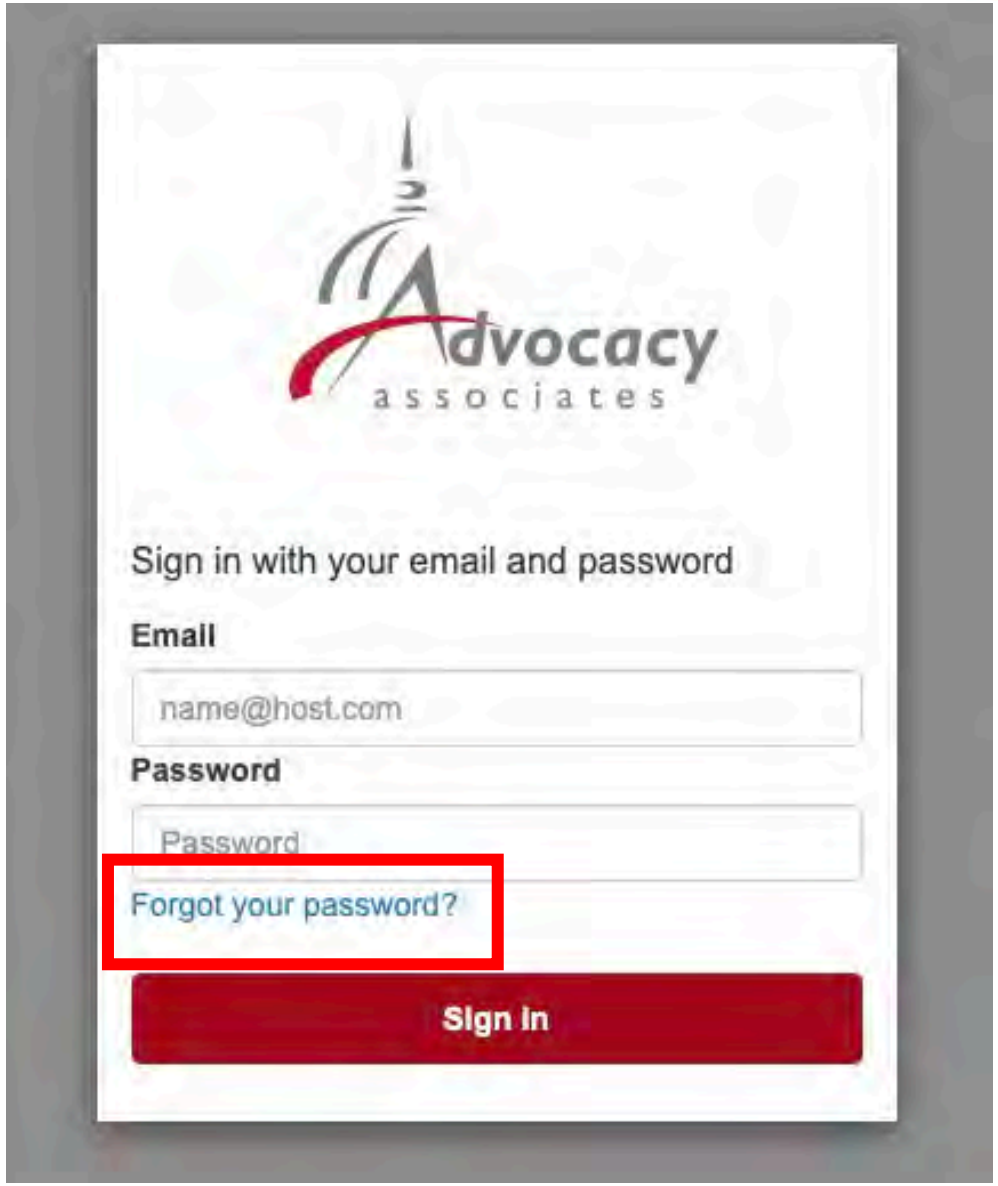
- Create your new password. Once completed, you will remain logged in when accessing your schedule again on this device



Accessing Your Schedule

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- If you forget your password and become logged out, you can create a new password through the “Forgot Password” link on the login page

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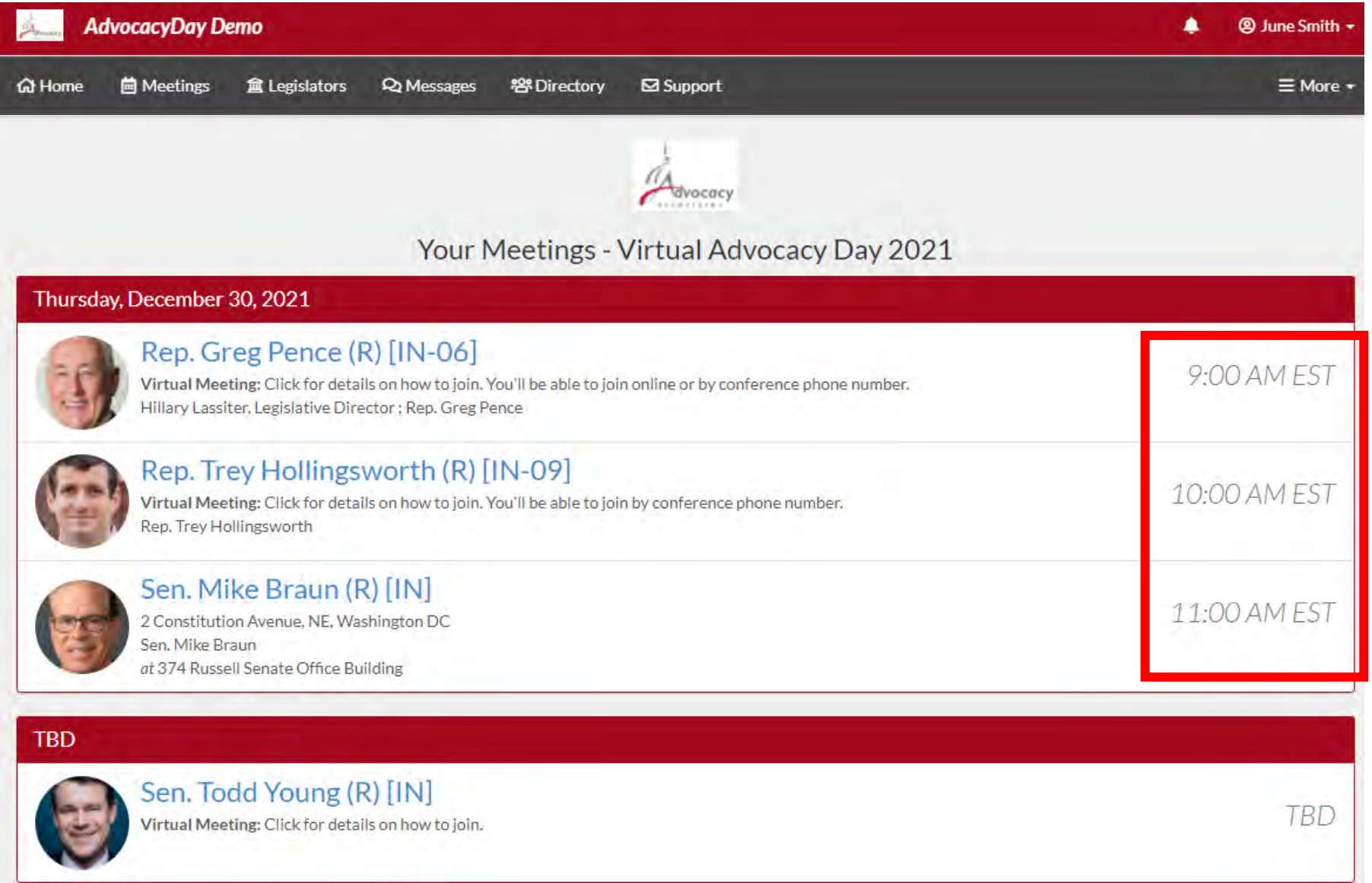
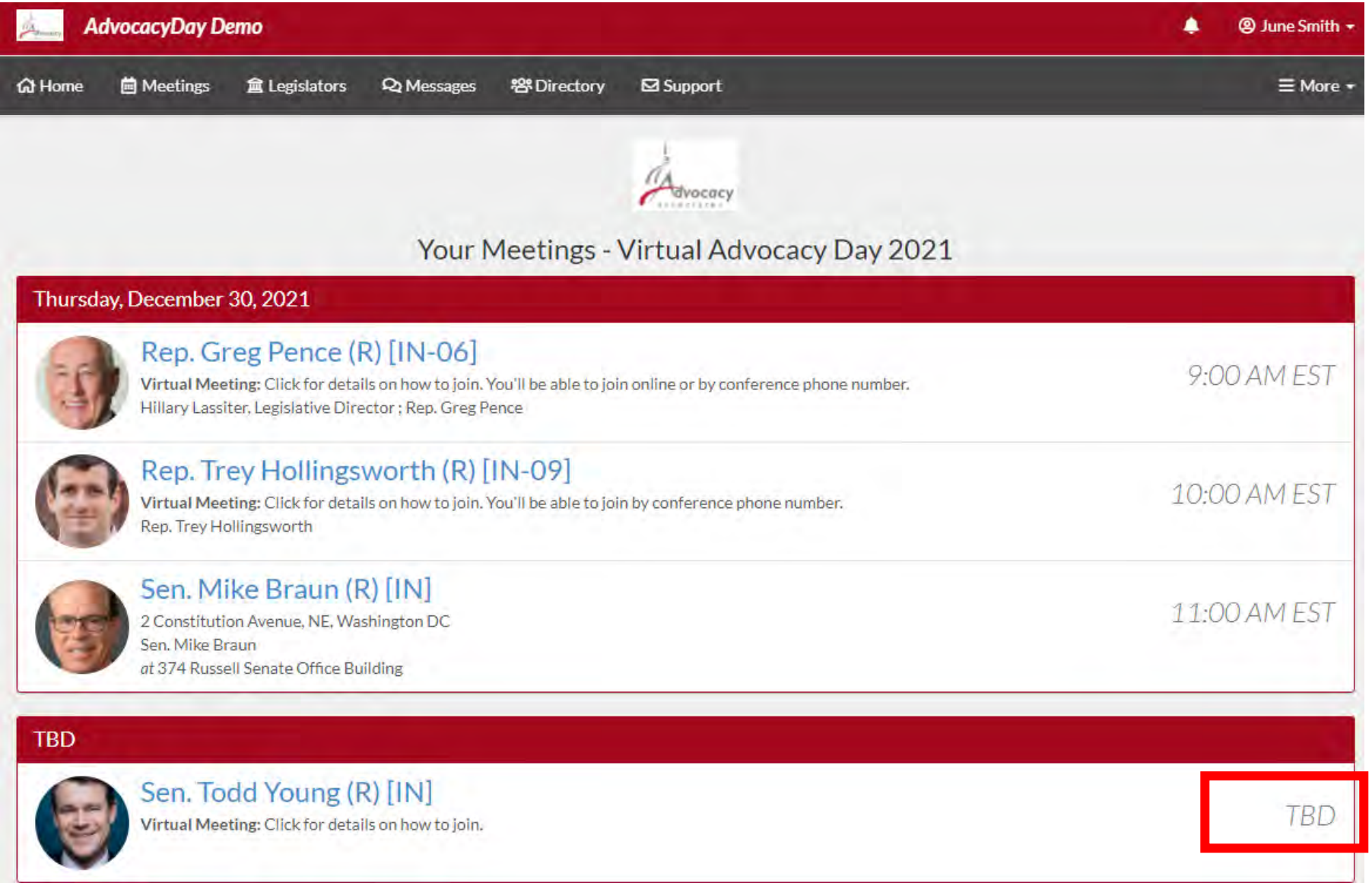
- If you forget your password and become logged out, you can create a new password through the "Forgot Password" link on the login page
- If you are still having technical issues when accessing your schedule, please visit Support through the link provided in your initial email



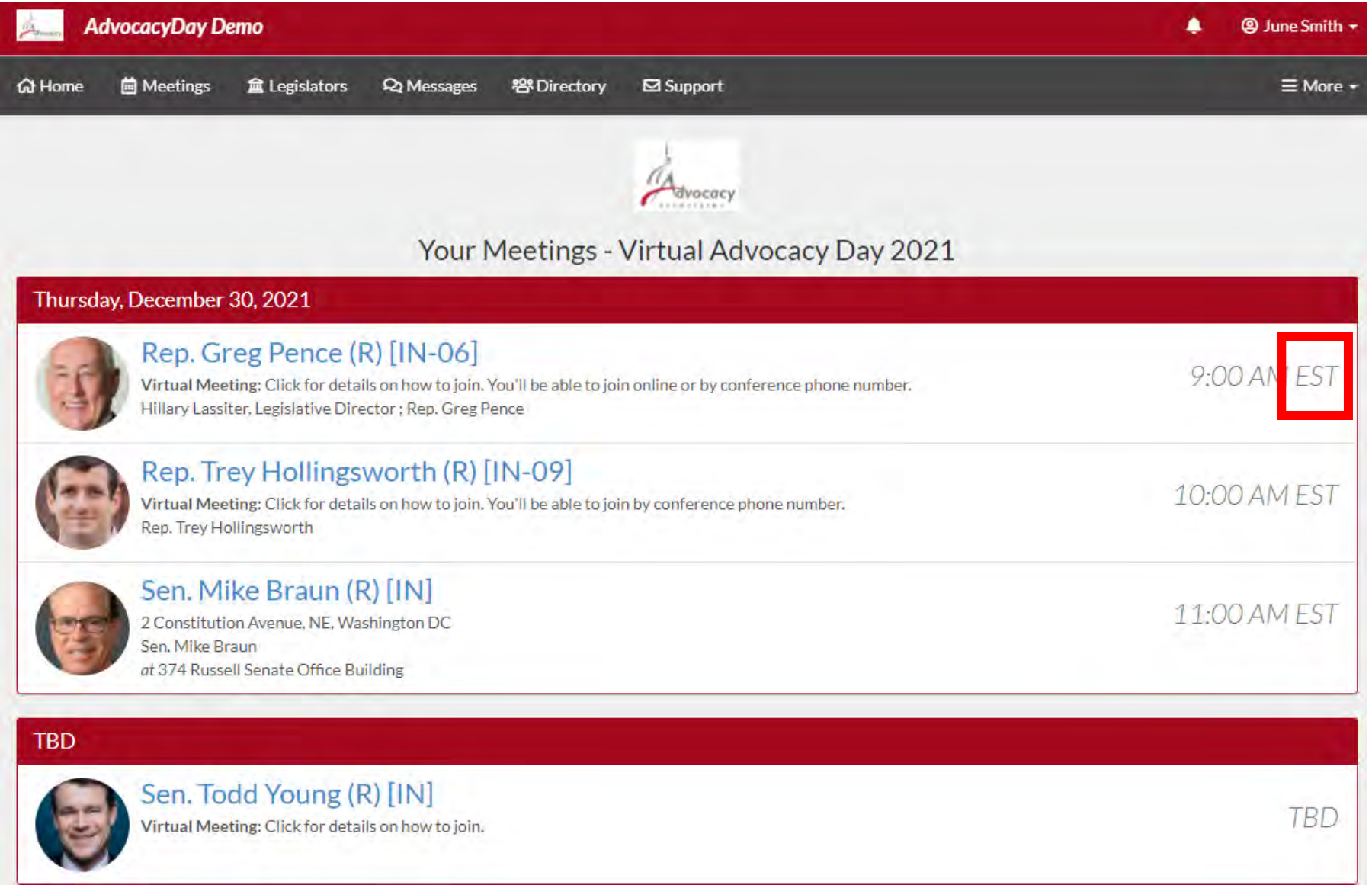
Main Schedule Page

- Confirmed meetings display with a time



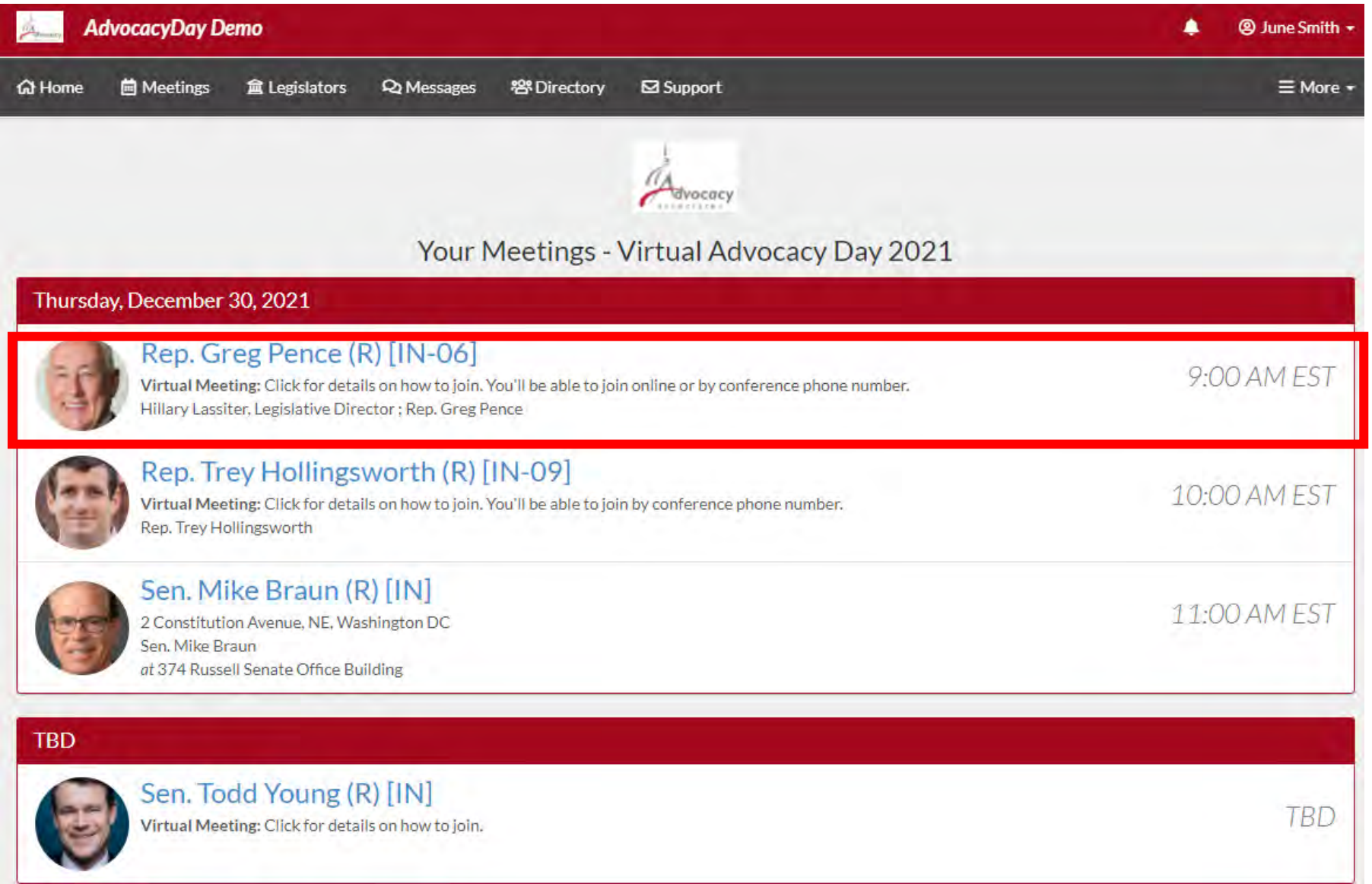
Main Schedule Page

- Confirmed meetings display with a time
- Pending meetings display on the bottom



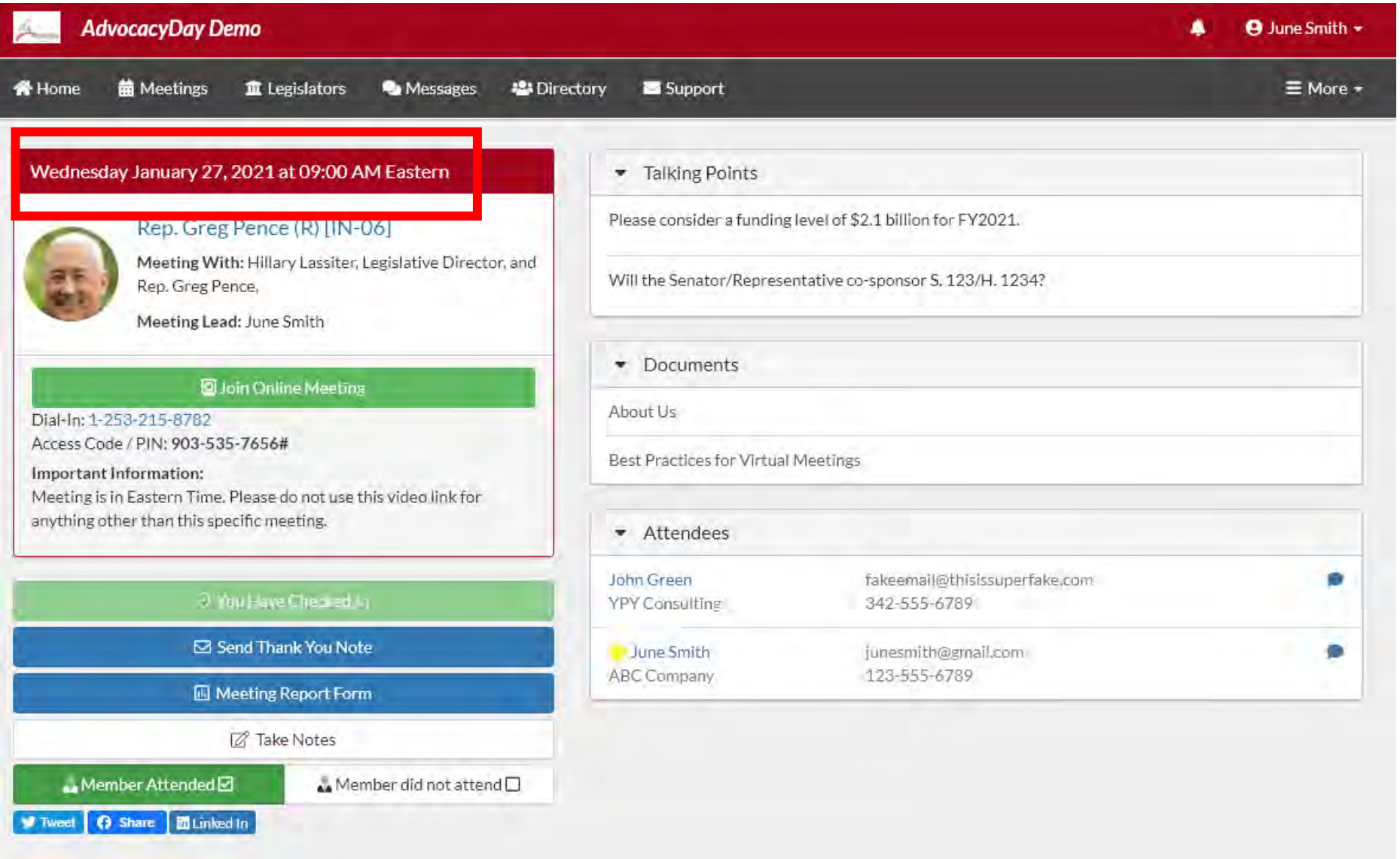
Main Schedule Page

- Confirmed meetings display with a time
- Pending meetings display on the bottom
- All times will be displayed in time zone you are located in

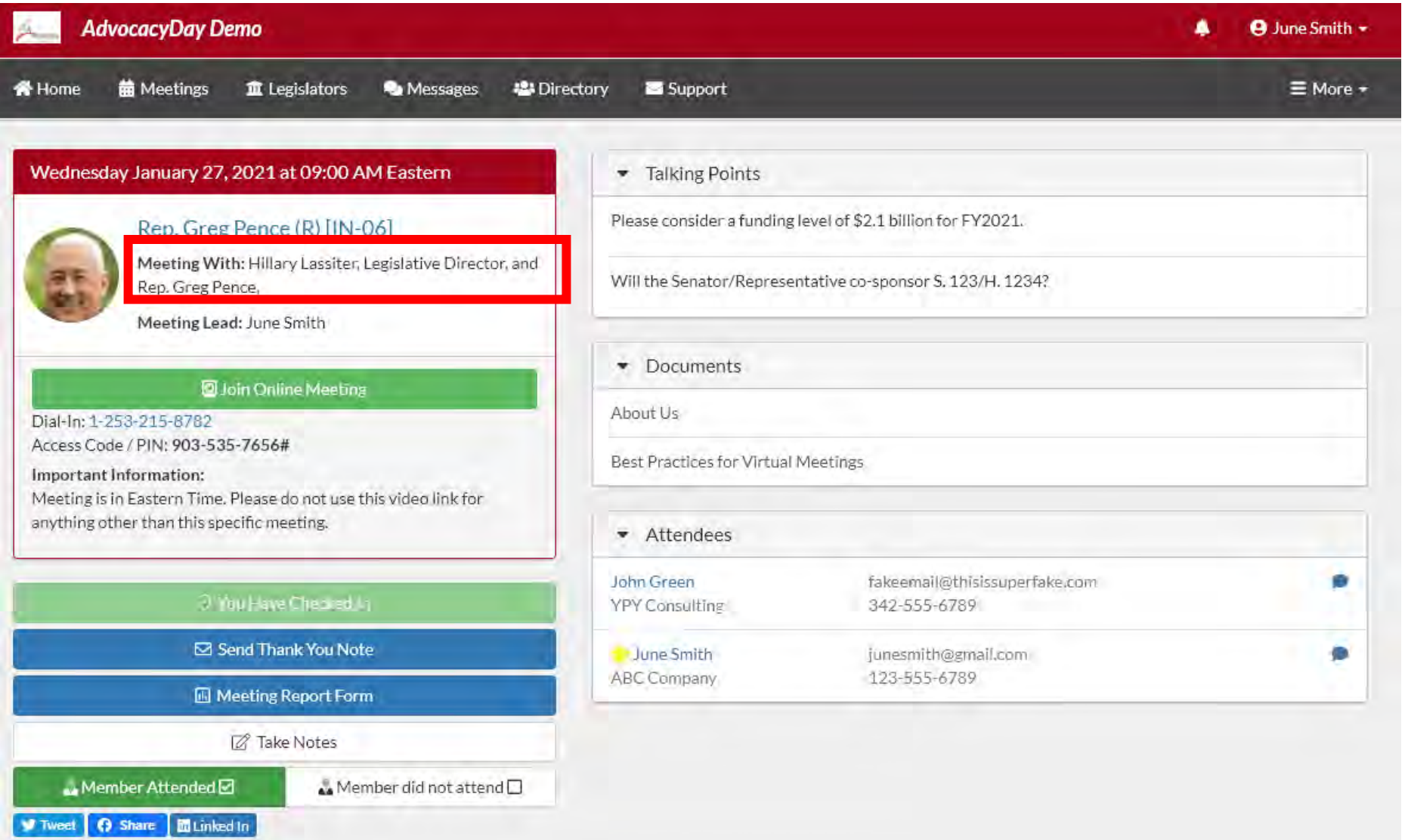


Main Schedule Page

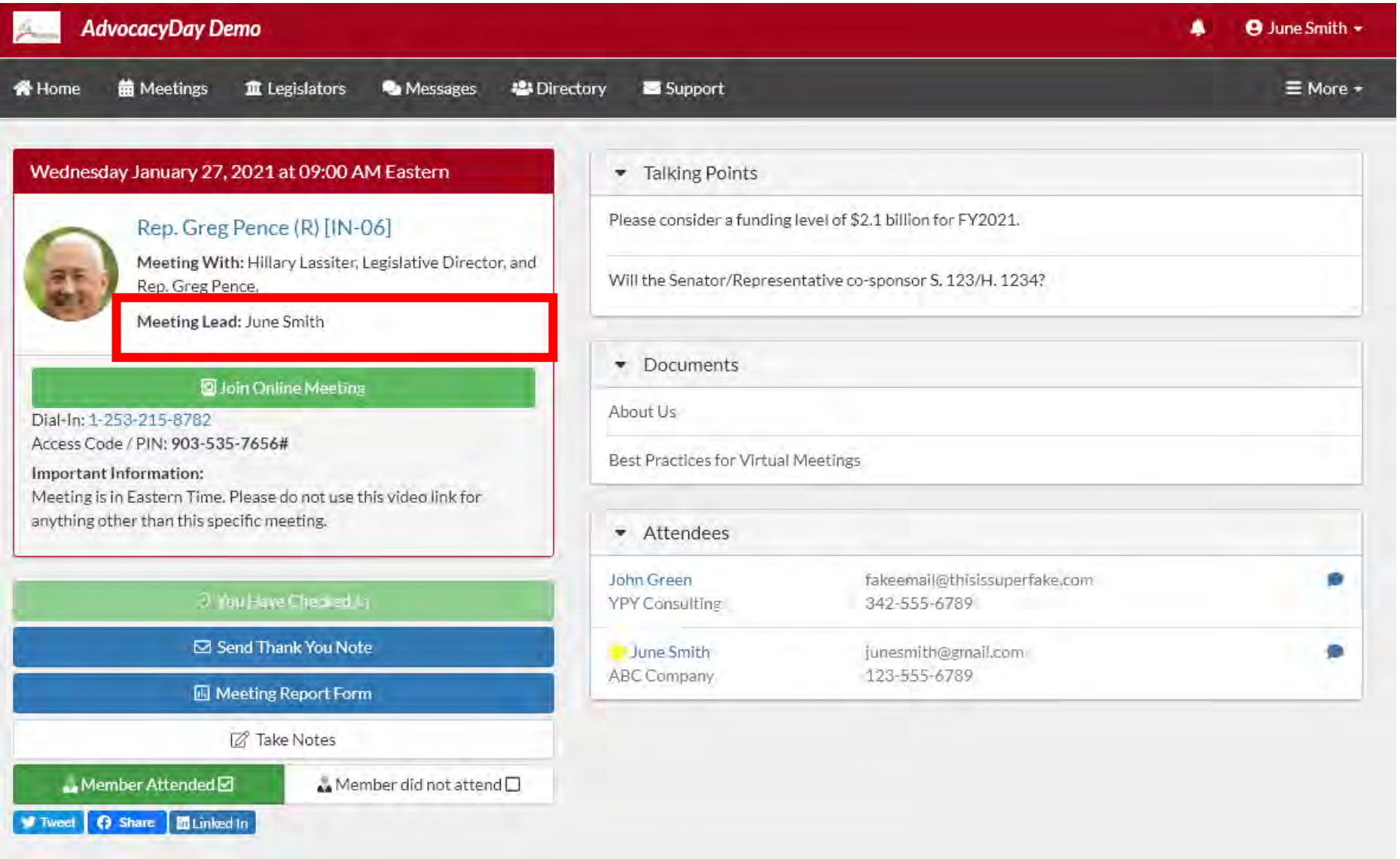
- Confirmed meetings display with a time
- Pending meetings display on the bottom
- All times will be displayed in time zone you are located in
- Click on each meeting to access the information



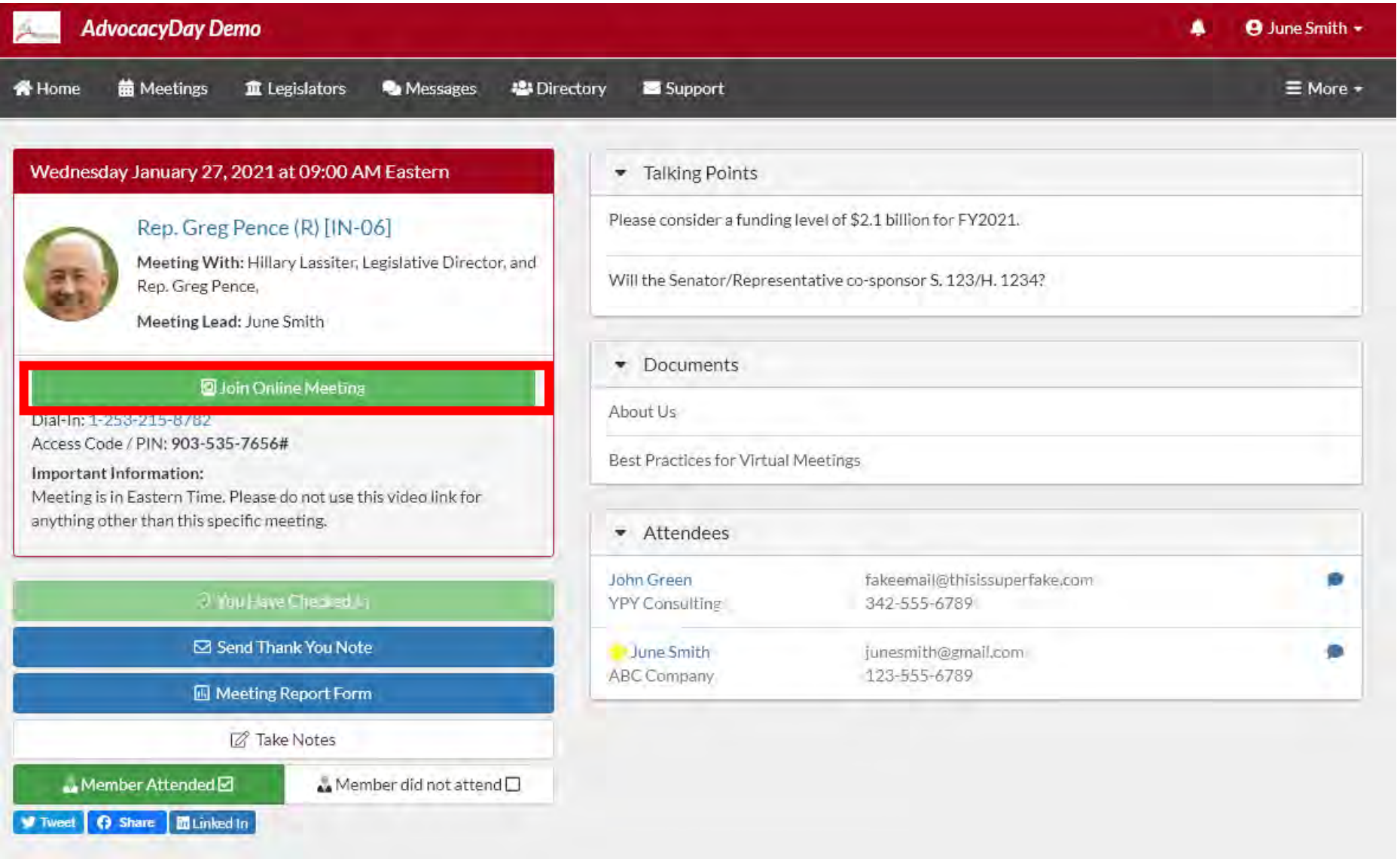
- Date and Time



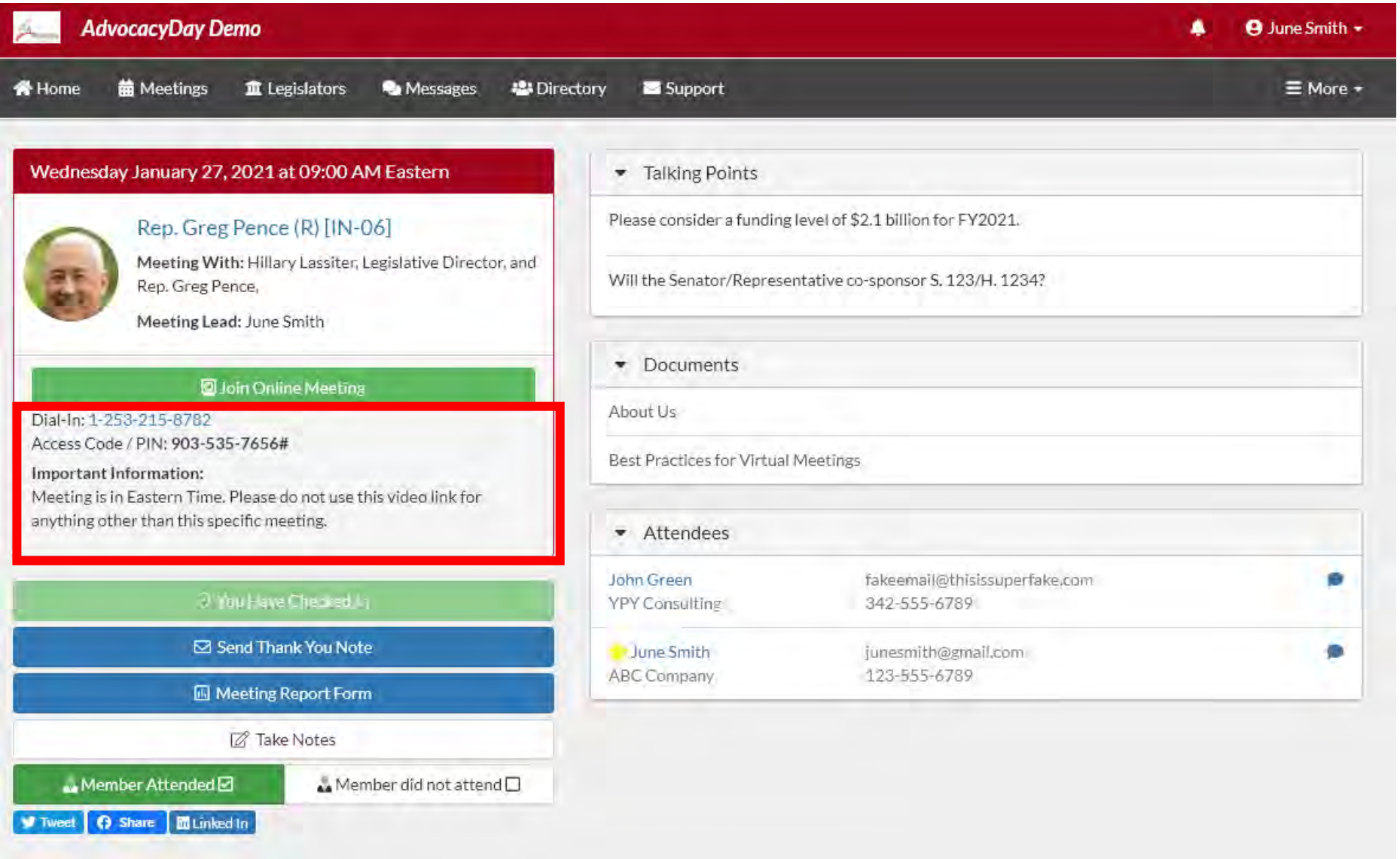
- Date and Time
- Meeting With



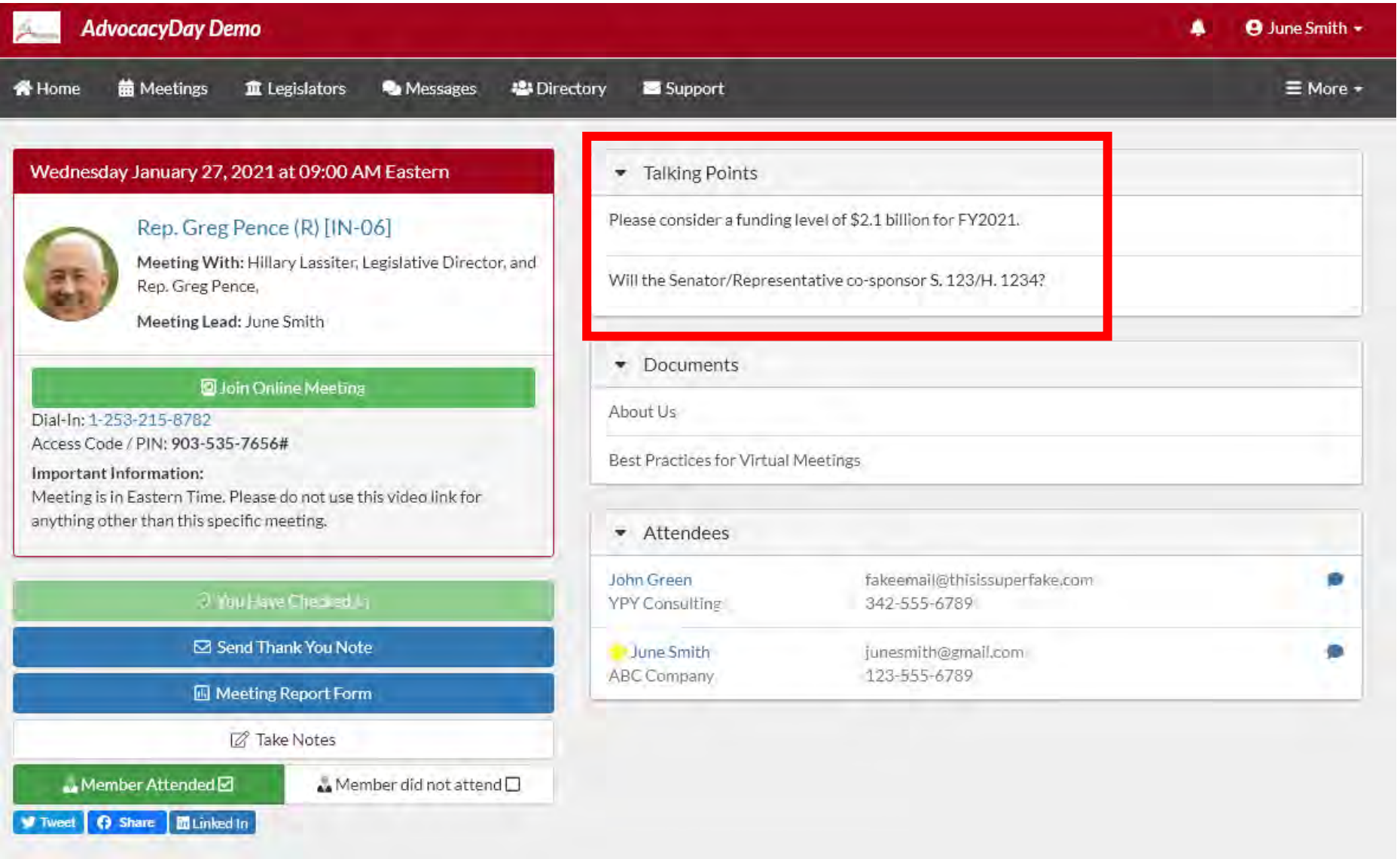
- Date and Time
- Meeting With
- Meeting Lead (if applicable)



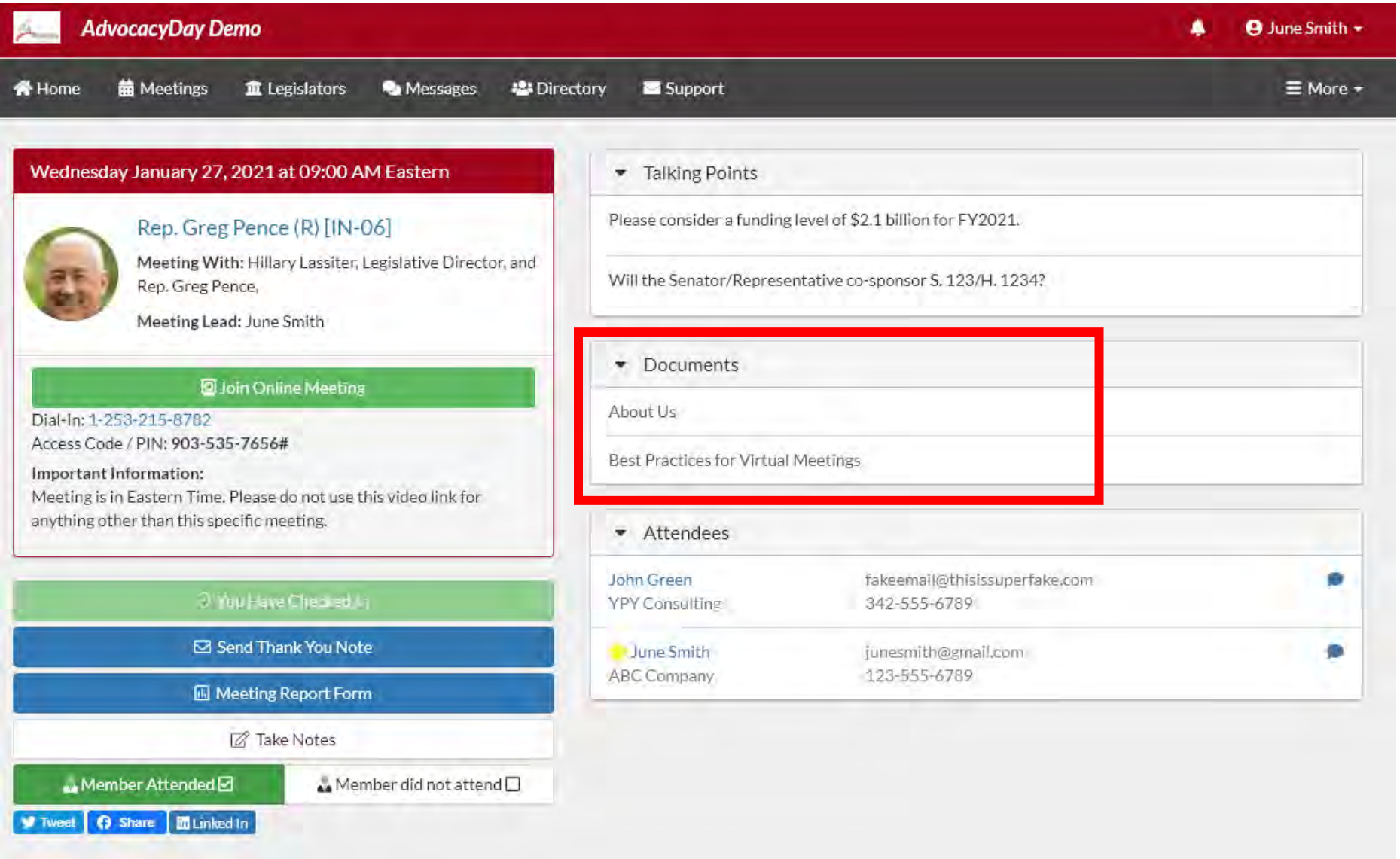
- Date and Time
- Meeting With
- Meeting Lead (if applicable)
- Click “Join Online Meeting” to open video component (not all meetings will have a video component)



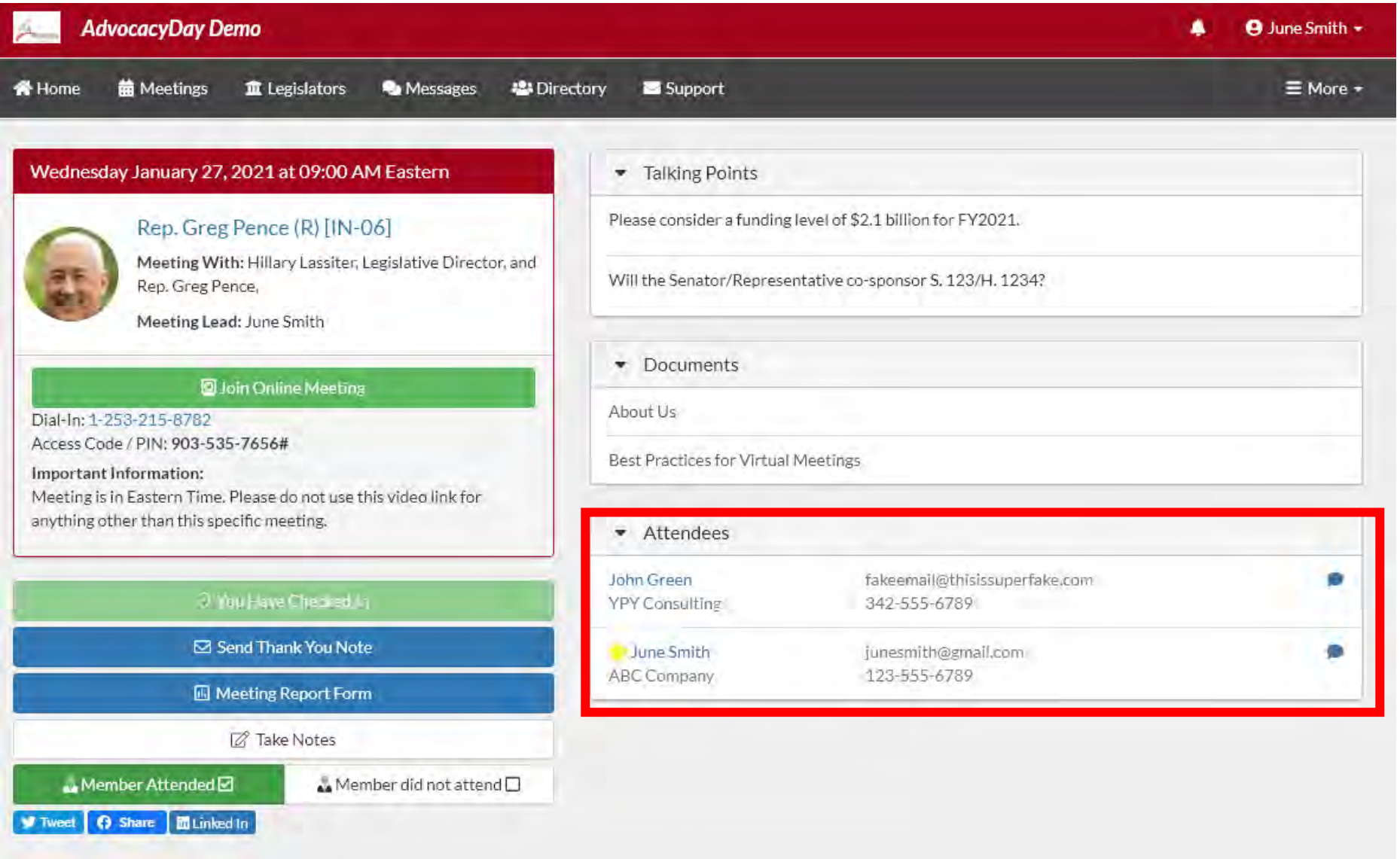
- Date and Time
- Meeting With
- Meeting Lead (if applicable)
- Click “Join Online Meeting” to open video component (not all meetings will have a video component)
- Dial-in/additional information



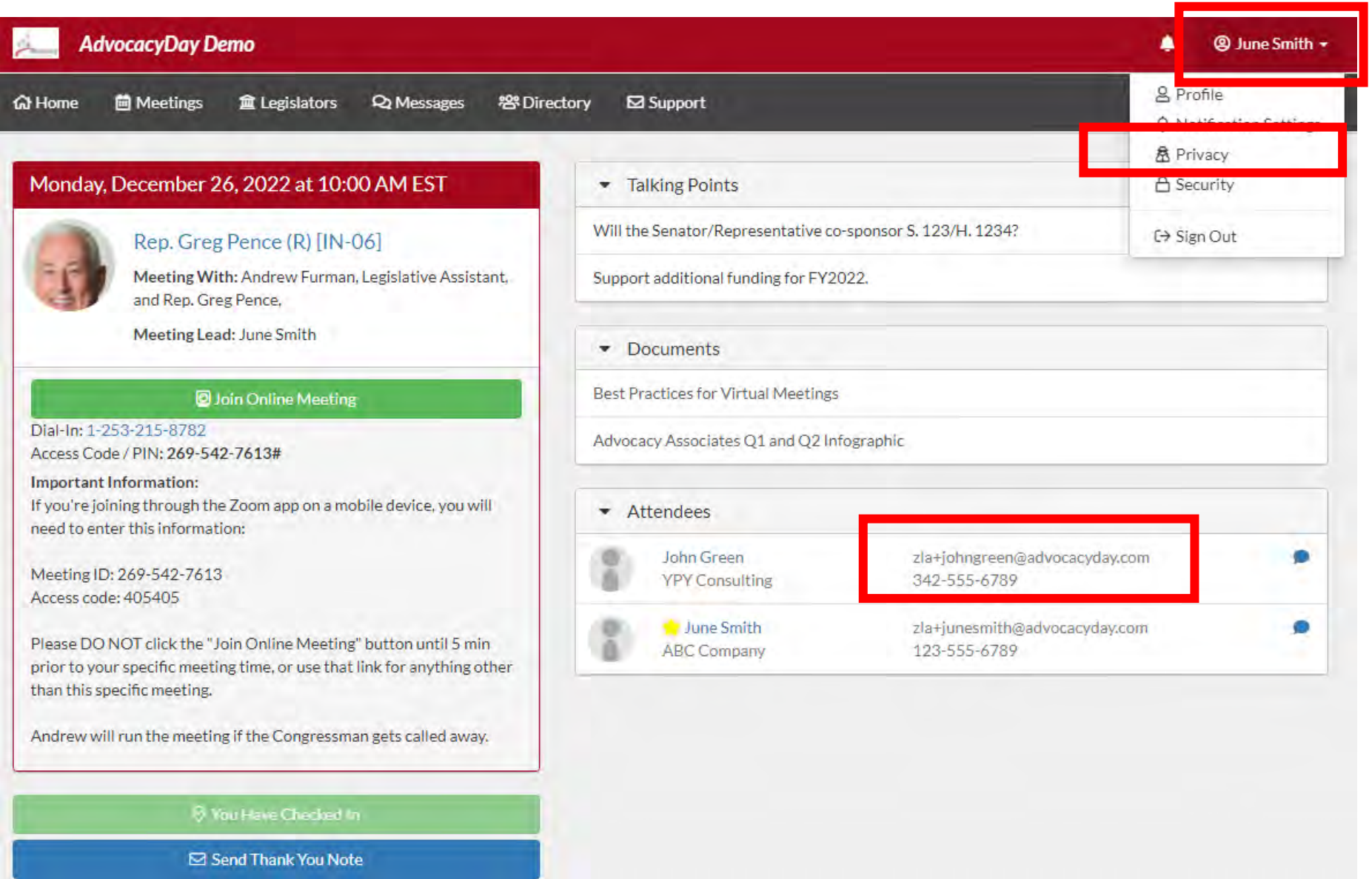
- Talking Points



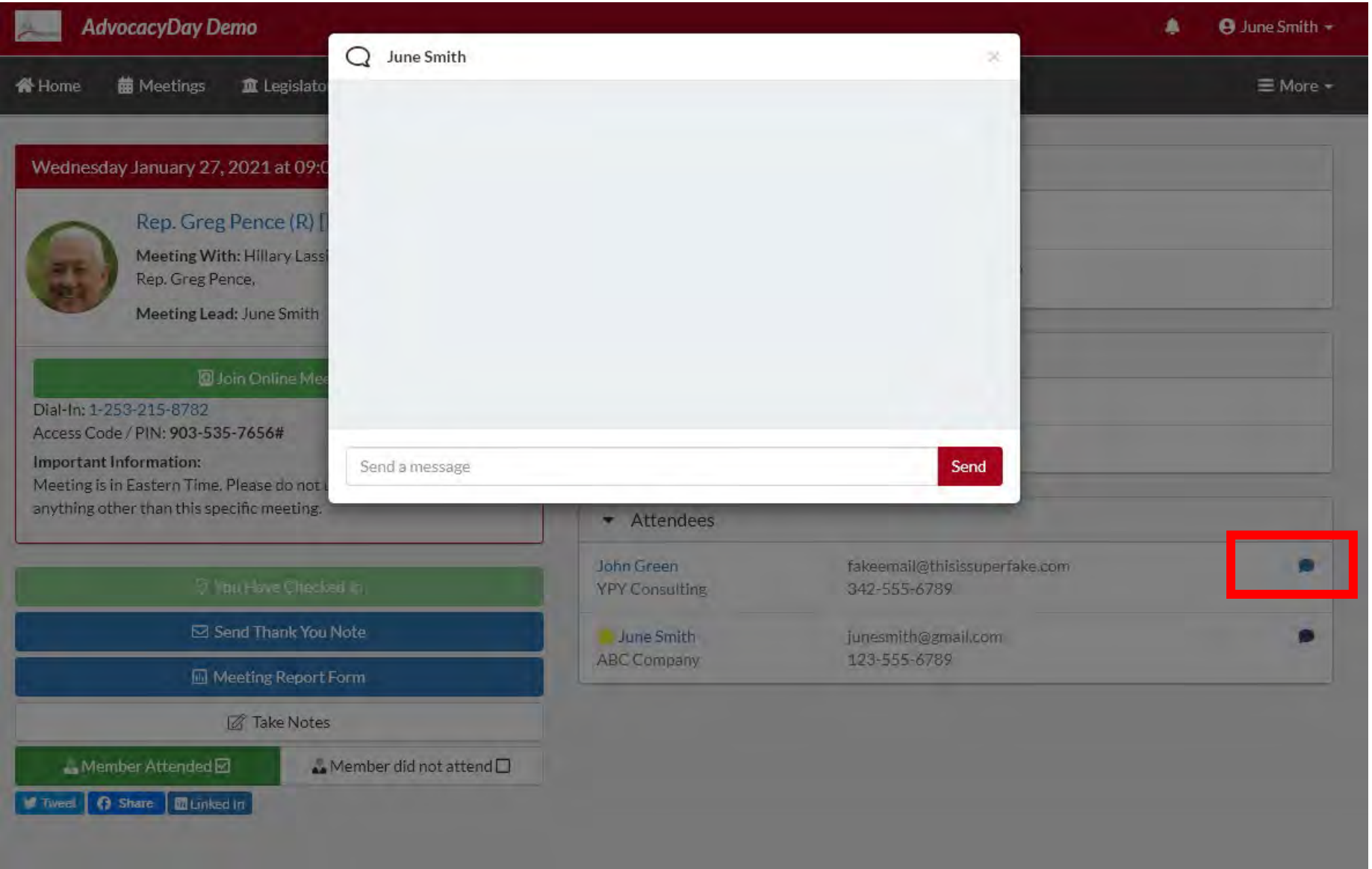
- Talking Points
- Documents (click to open in separate tab)



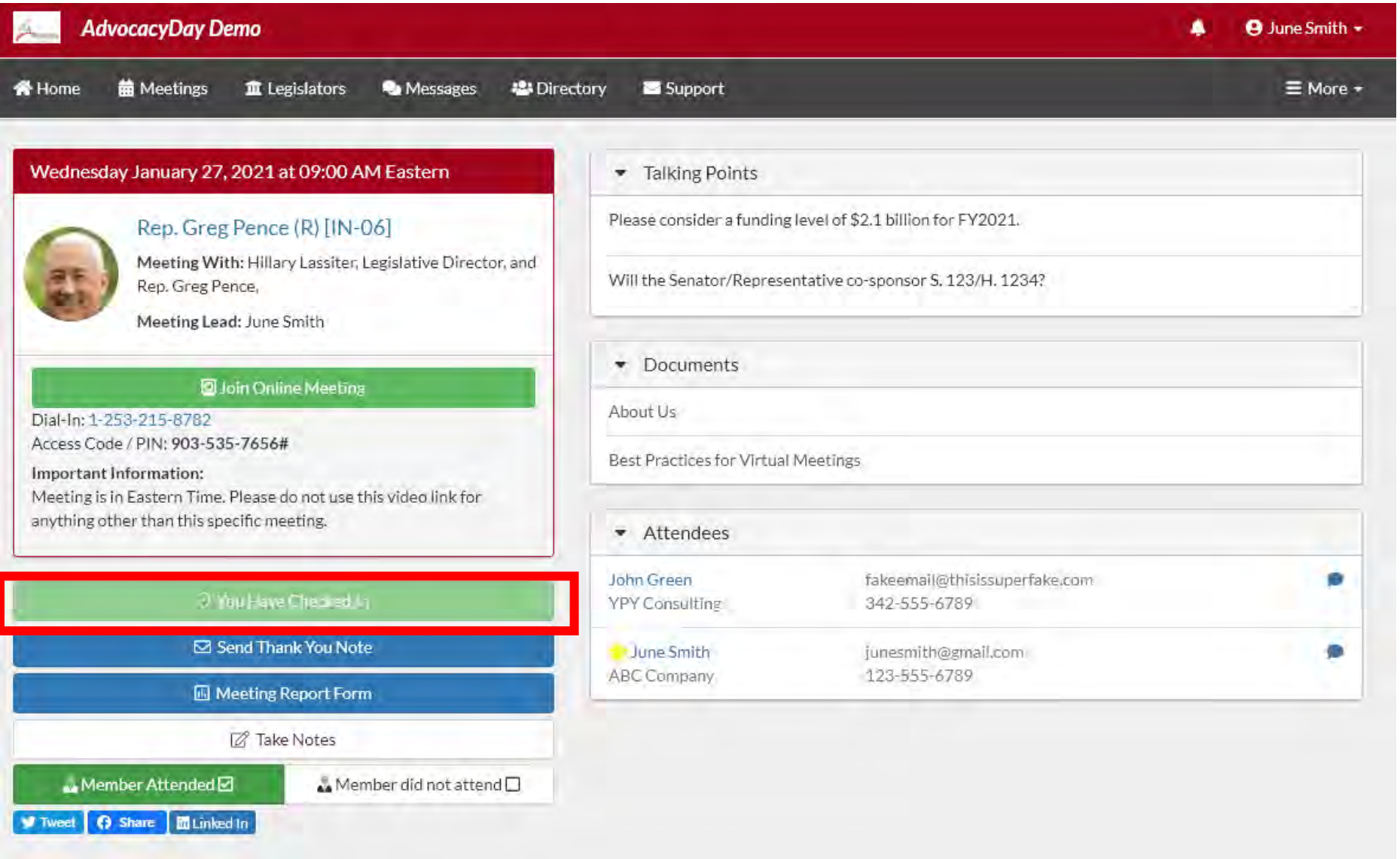
- Talking Points
- Documents (click to open in separate tab)
- Attendees who are in the meeting



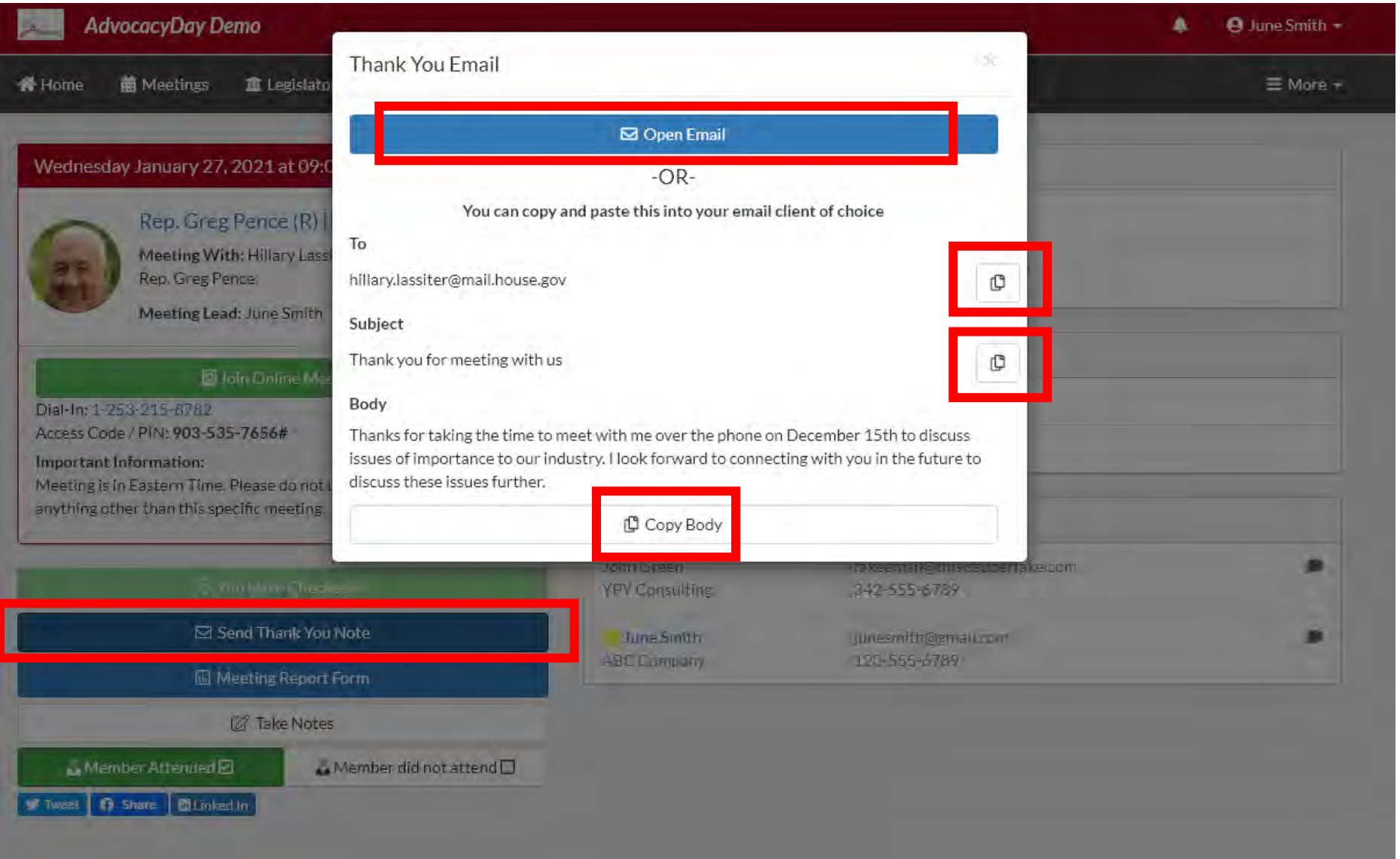
- Talking Points
- Documents (click to open in separate tab)
- Attendees who are in the meeting
- Turn on/off your contact information. Click on your name in upper right corner, click Privacy tab



- Talking Points
- Documents (click to open in separate tab)
- Attendees who are in the meeting
- Turn on/off your contact information. Click on your name in upper right corner, click Privacy tab
- Peer-to-peer chat function

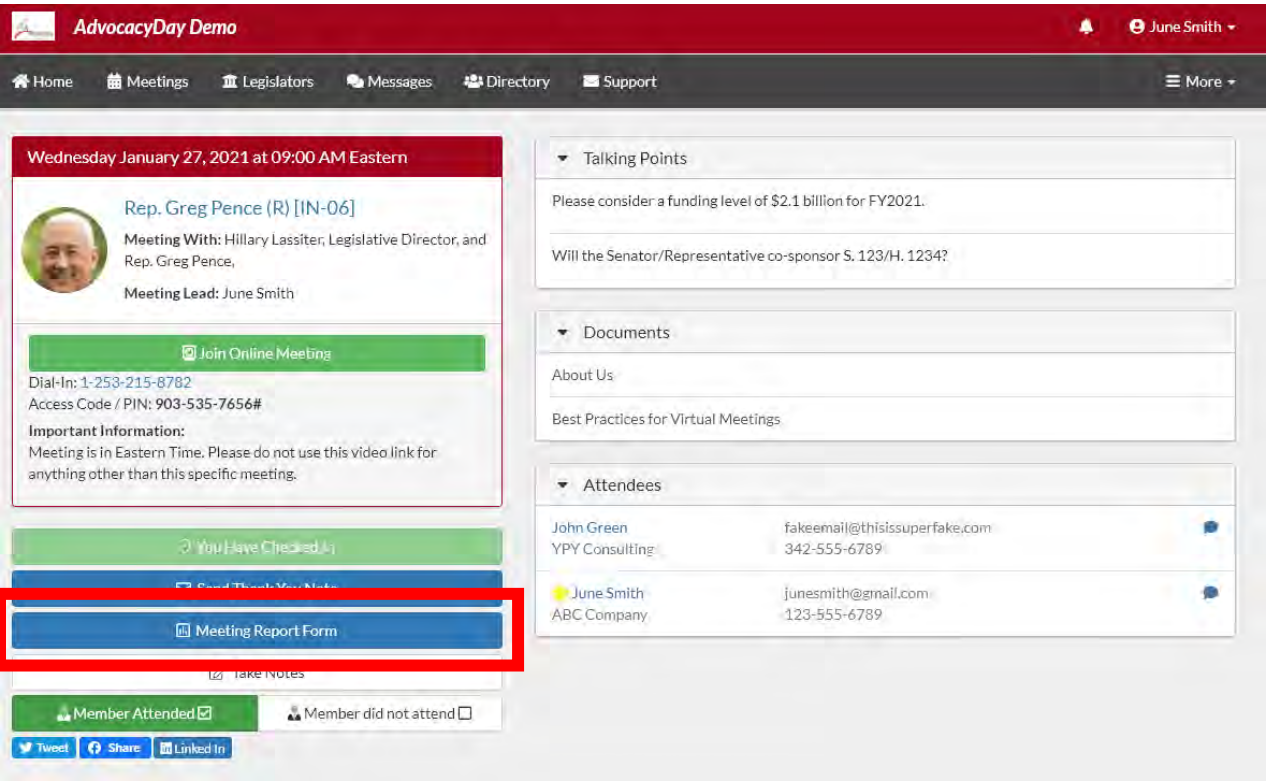


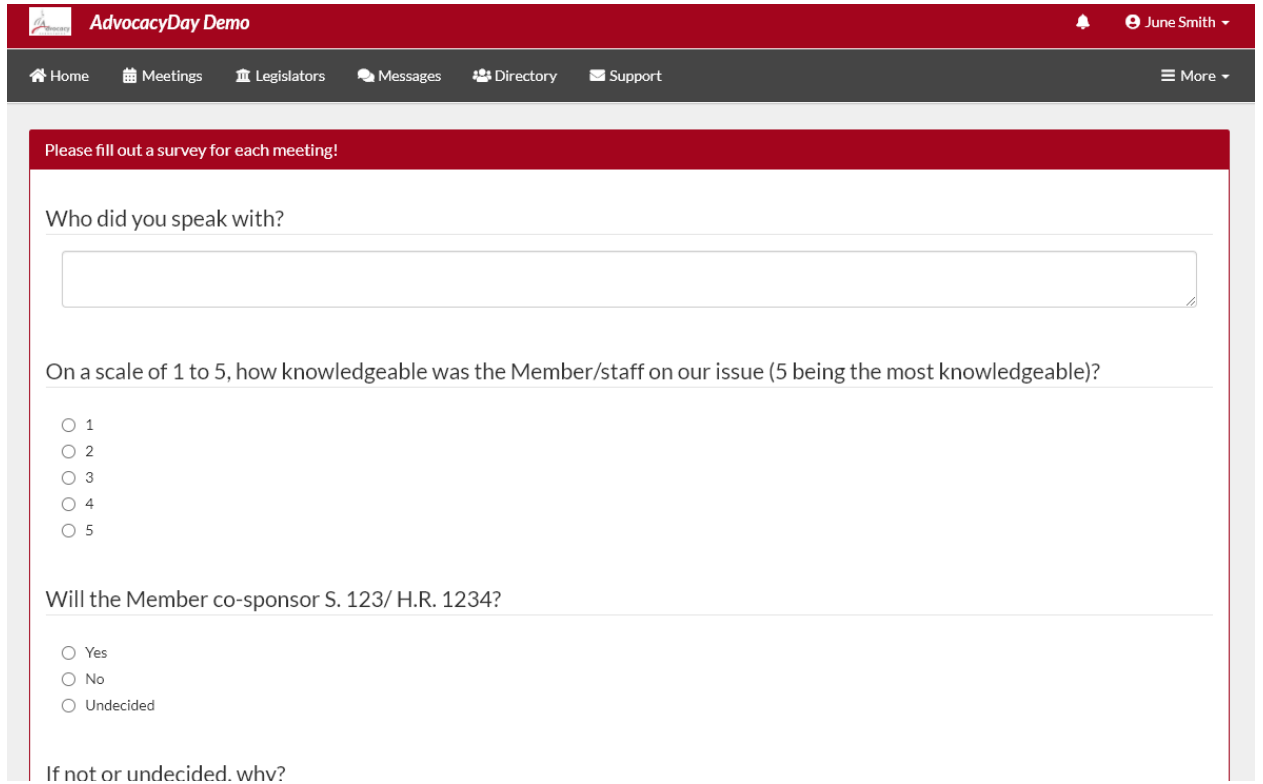
- Check-in to report attendance



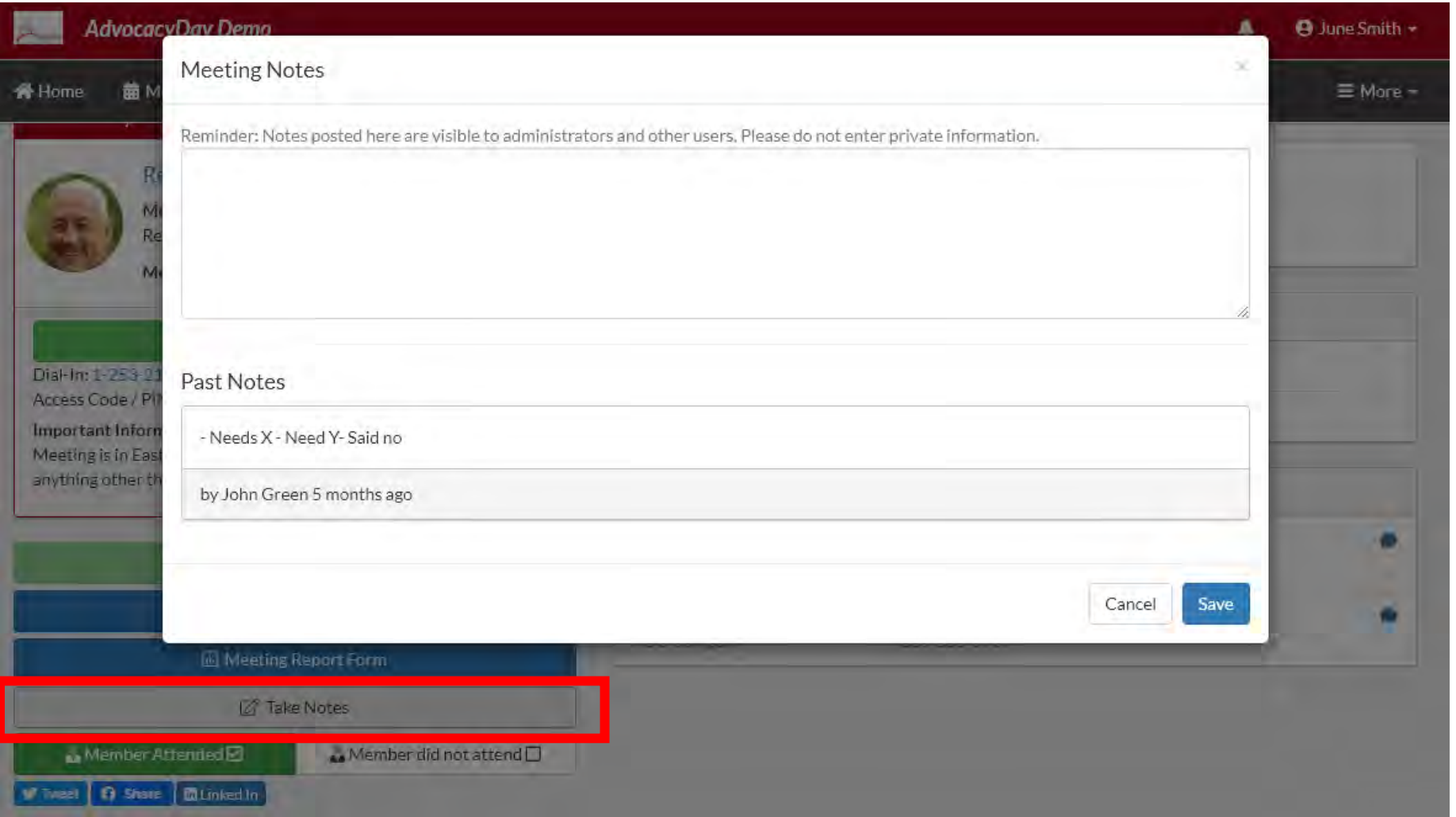
- Check in to report attendance
- Thank You email. Open the email with your native platform or copy/paste into Gmail, Yahoo, AOL etc.

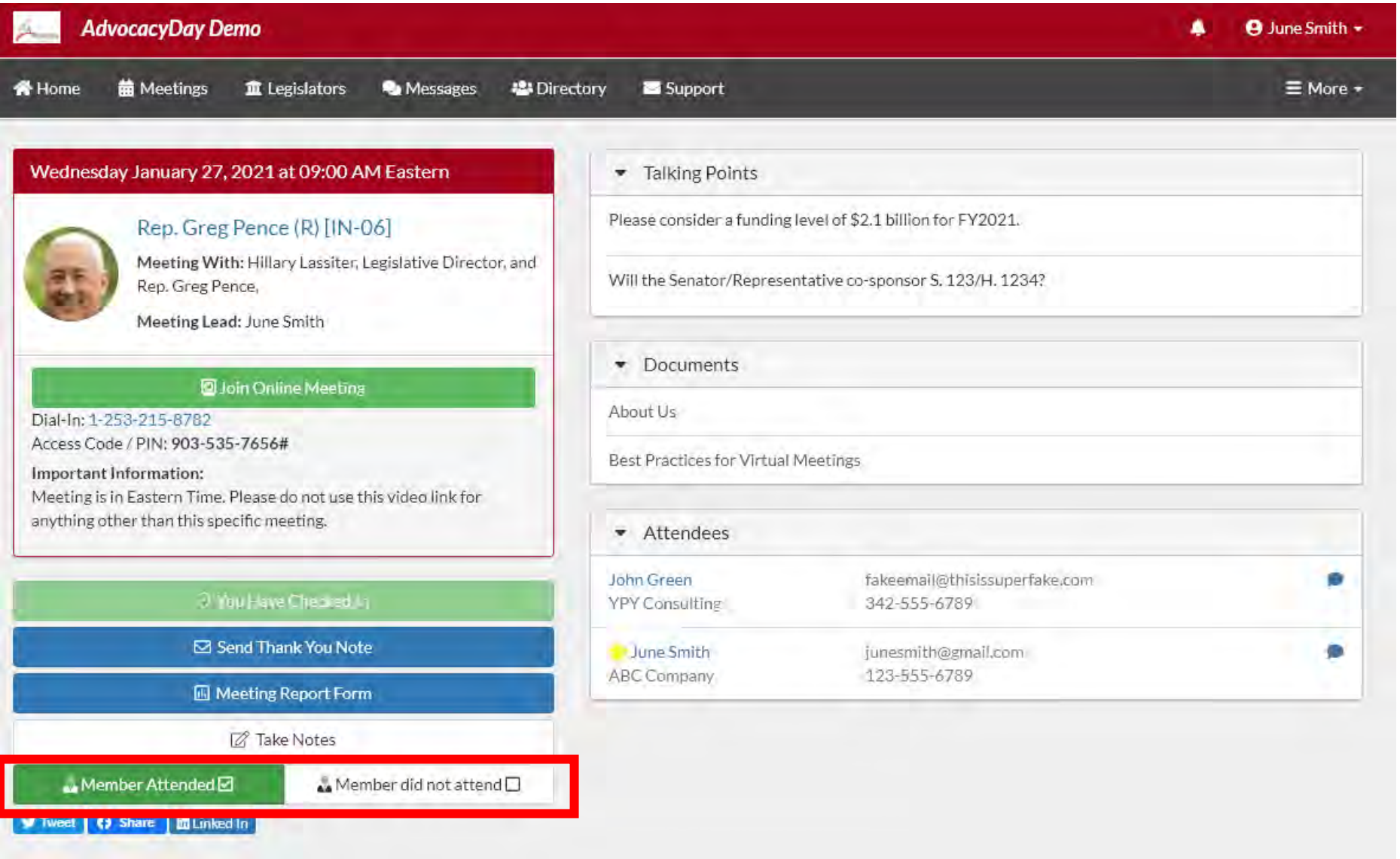
- Meeting Report Form, scroll down to answer each question



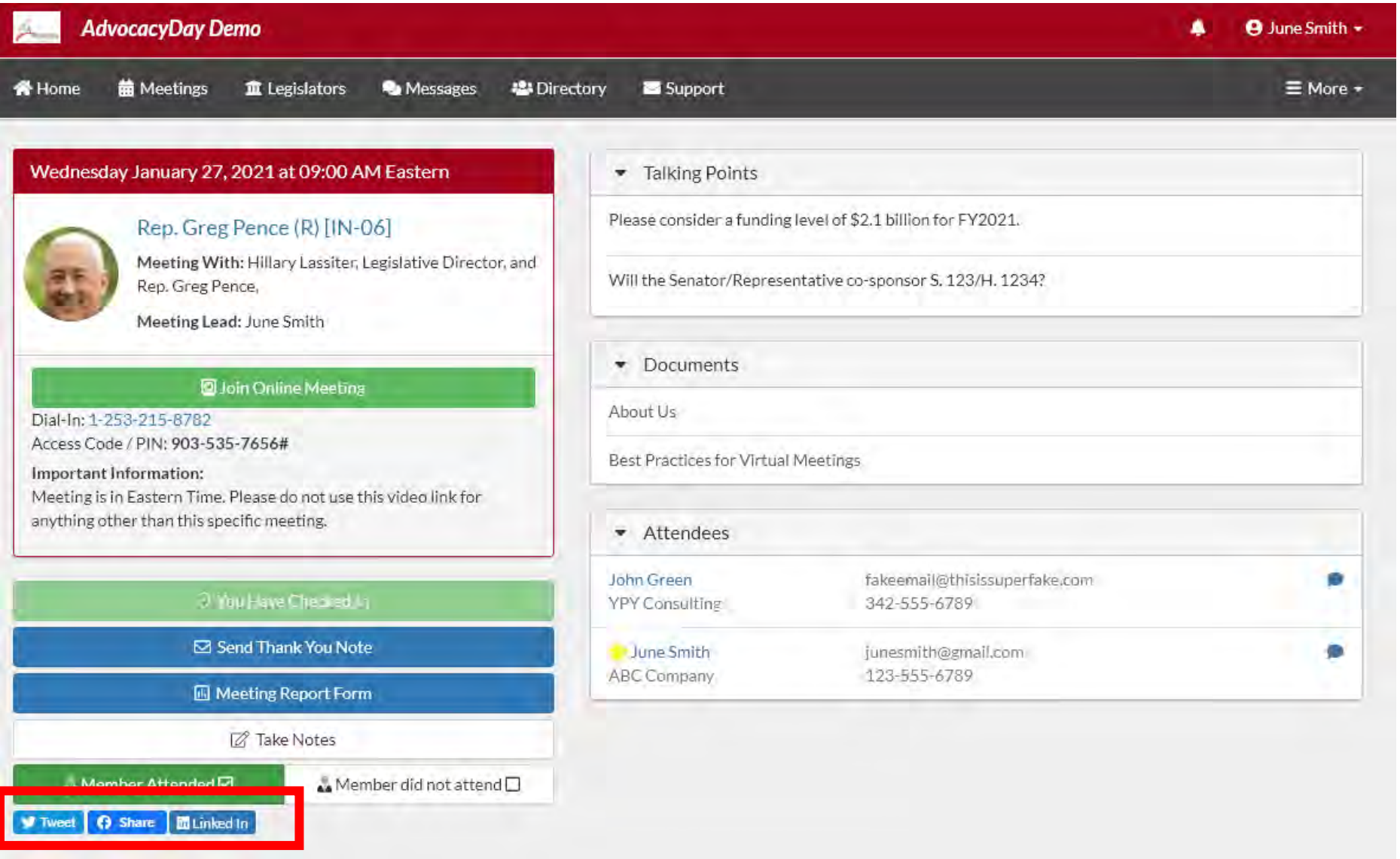


- Take Notes option (blank notepad)

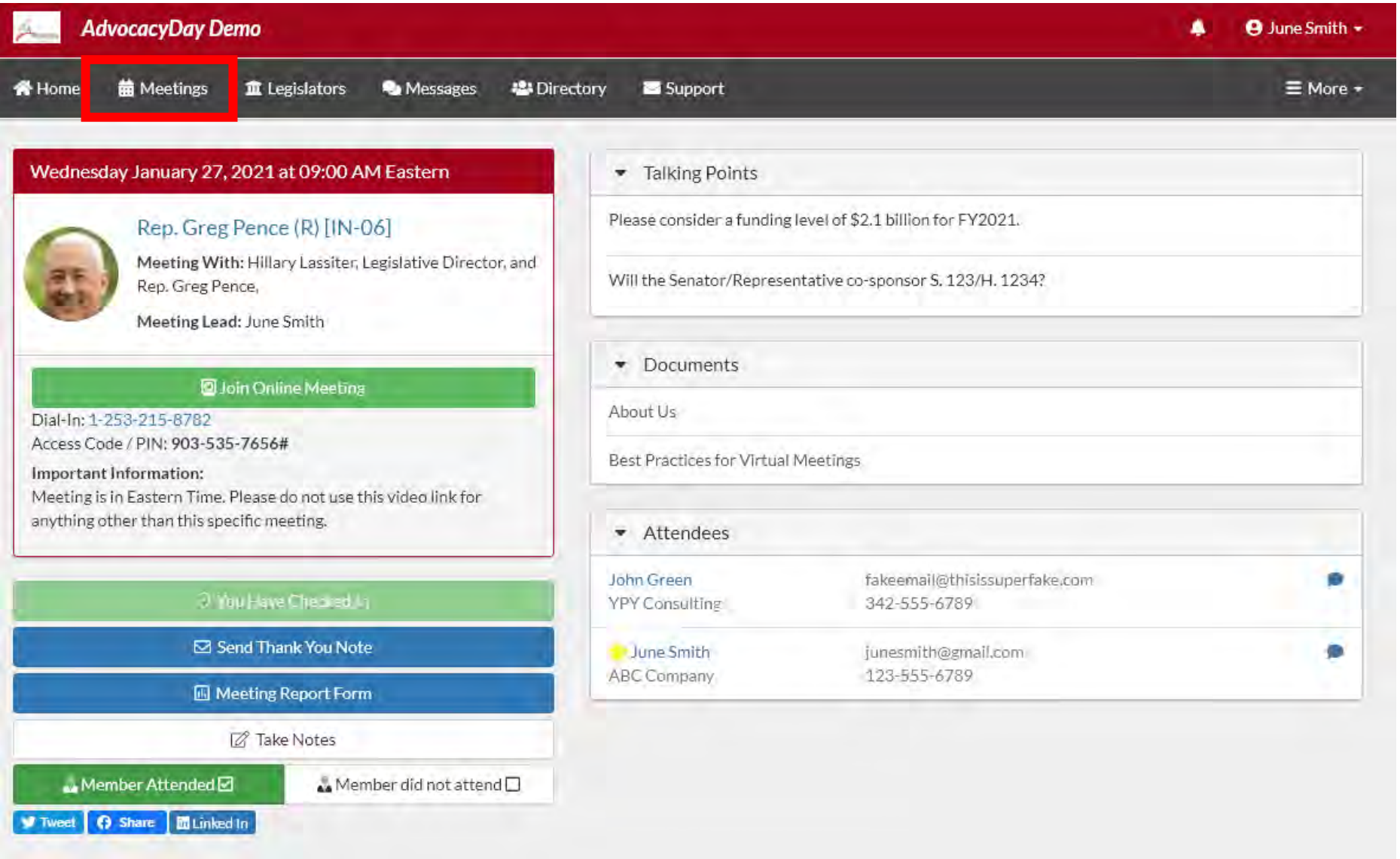




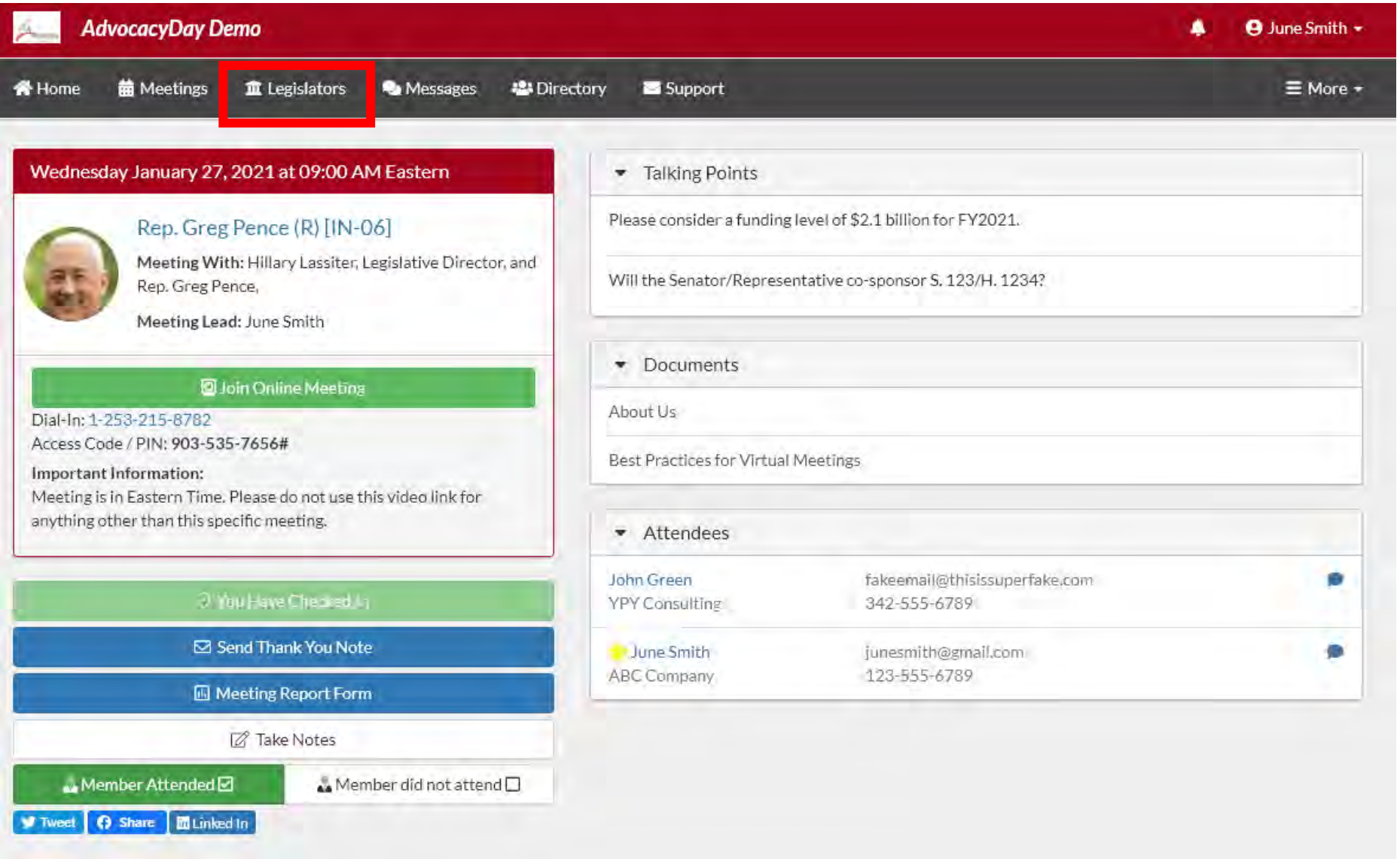
- Take Notes option (blank notepad)
- Member of Congress attendance, check one



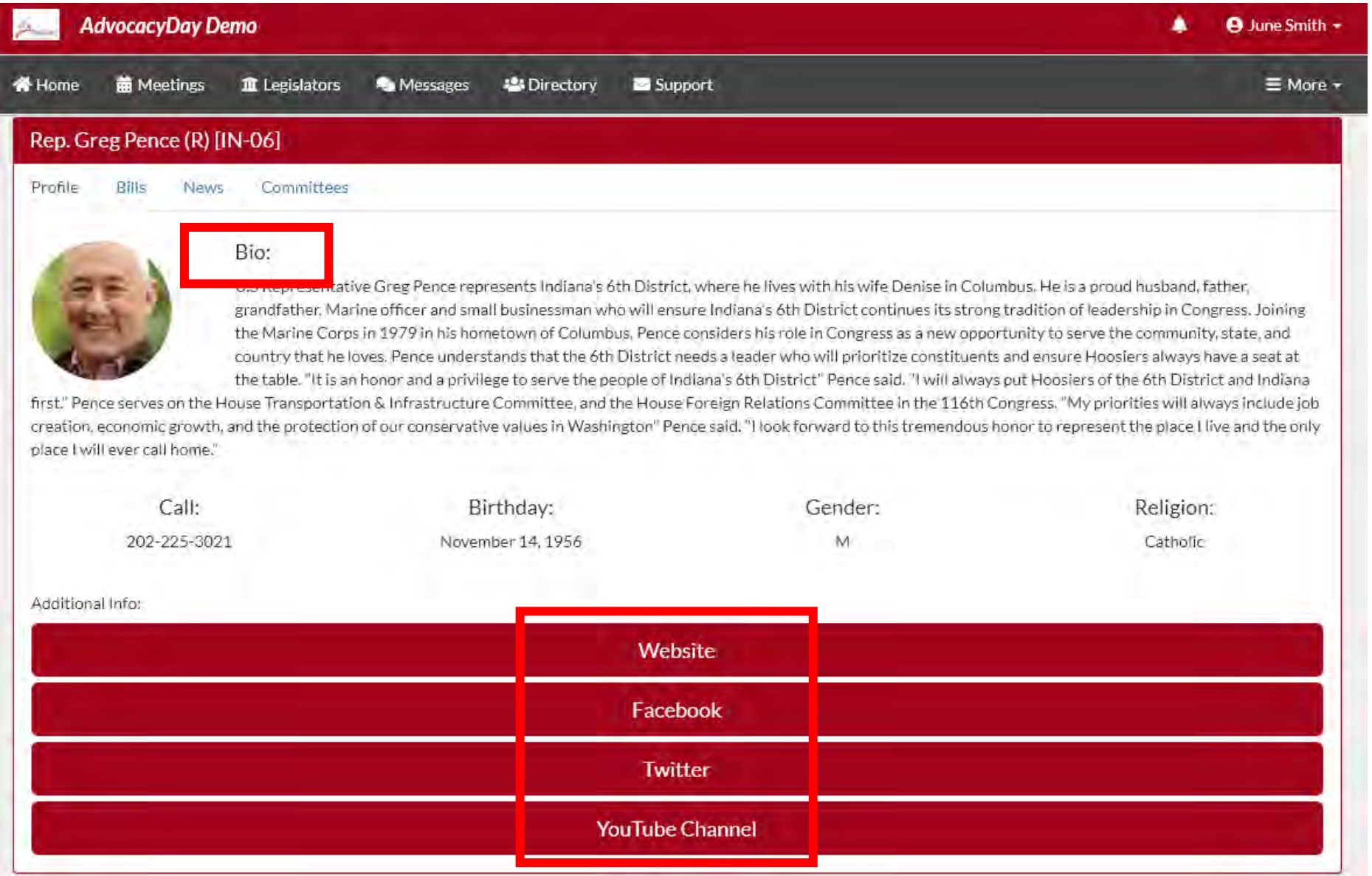
- Take Notes option (blank notepad)
- Member of Congress attendance, check one
- Social Media share buttons



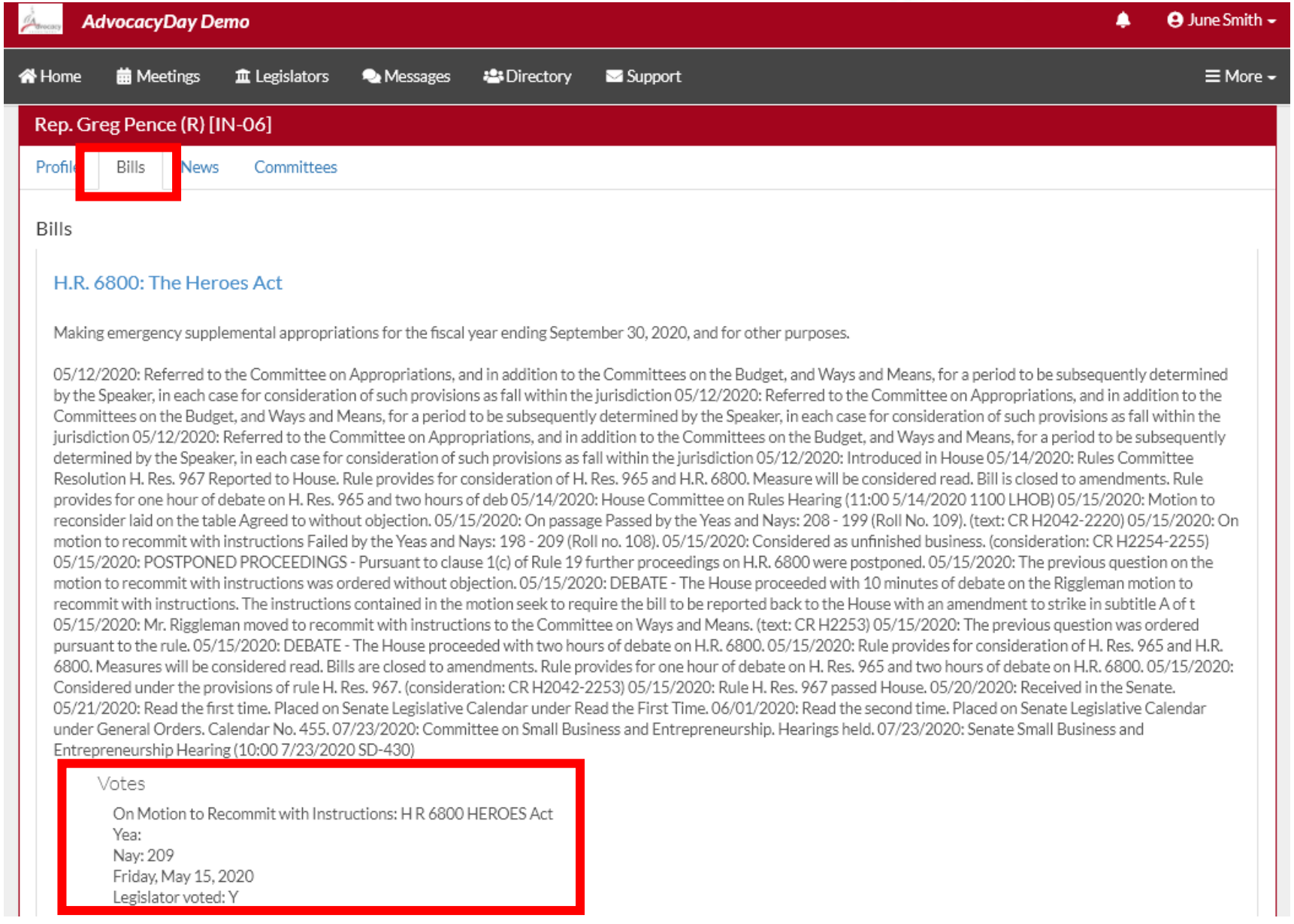
- Take Notes option (blank notepad)
- Member of Congress attendance, check one
- Social Media share buttons
- Click on Meetings tab to access main page again



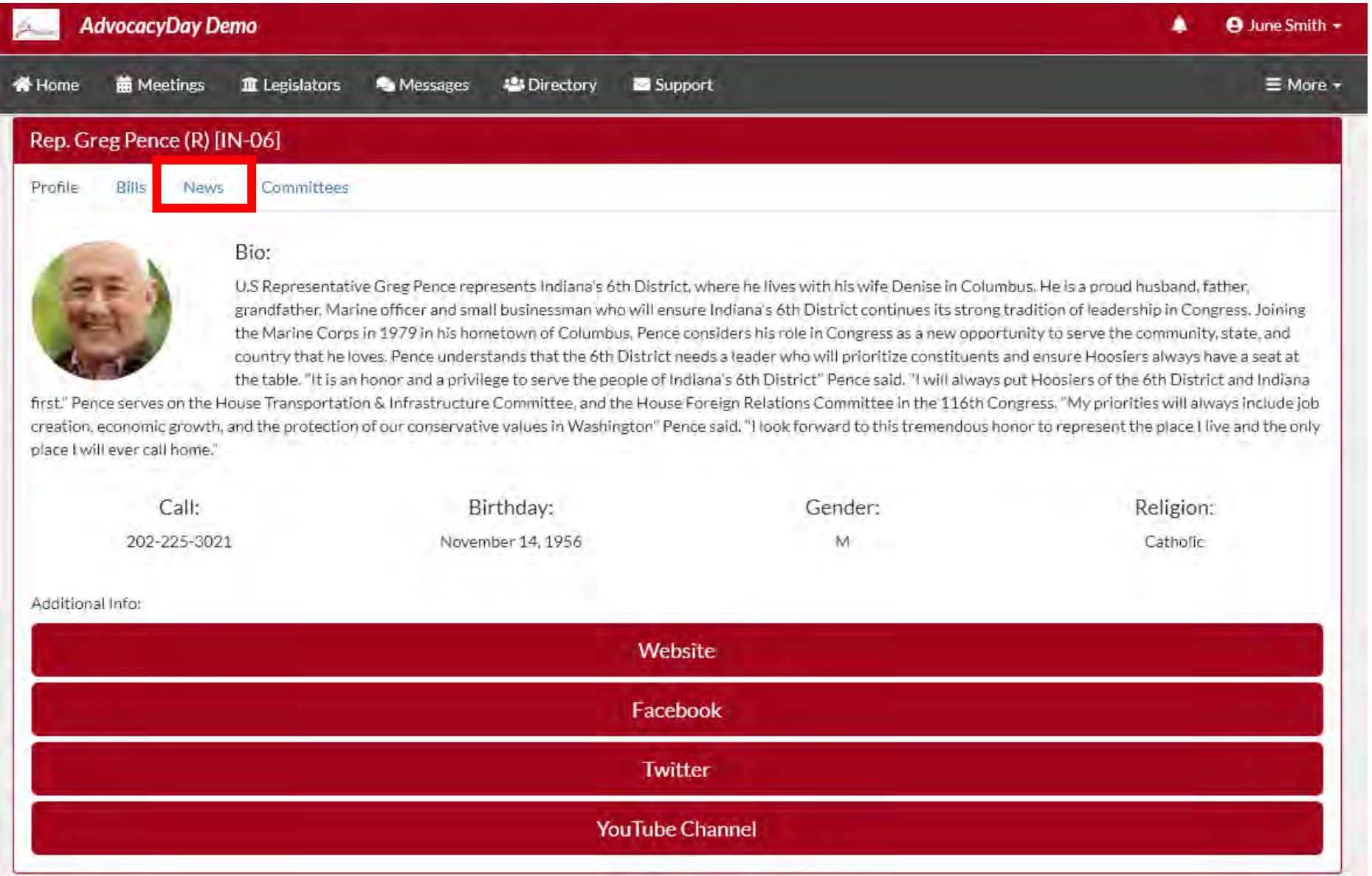
- Take Notes option (blank notepad)
- Member of Congress attendance, check one
- Social Media share buttons
- Click on Meetings tab to access main page again
- Click Legislators tab to access more information



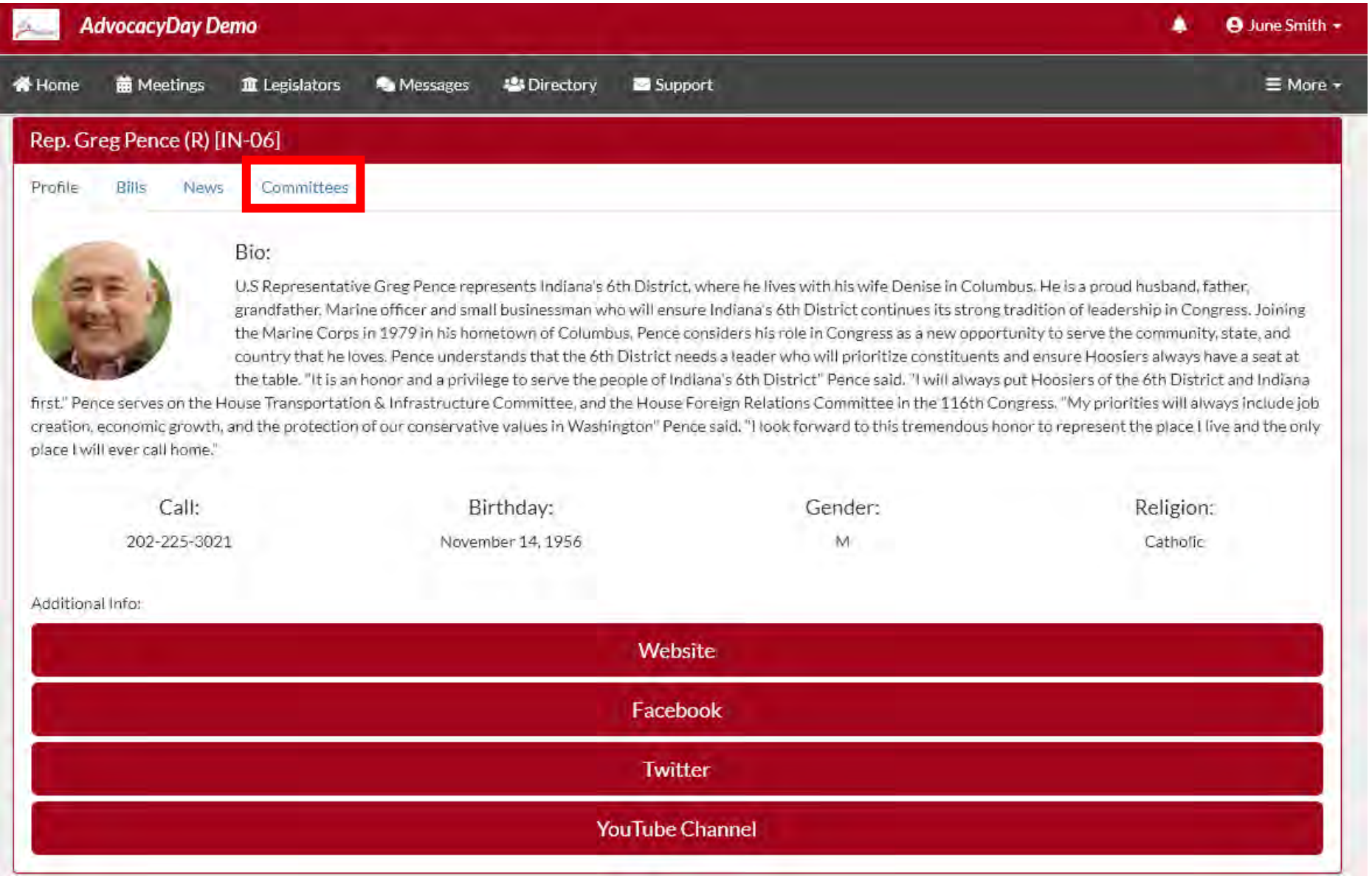
- Bio and social media contact information



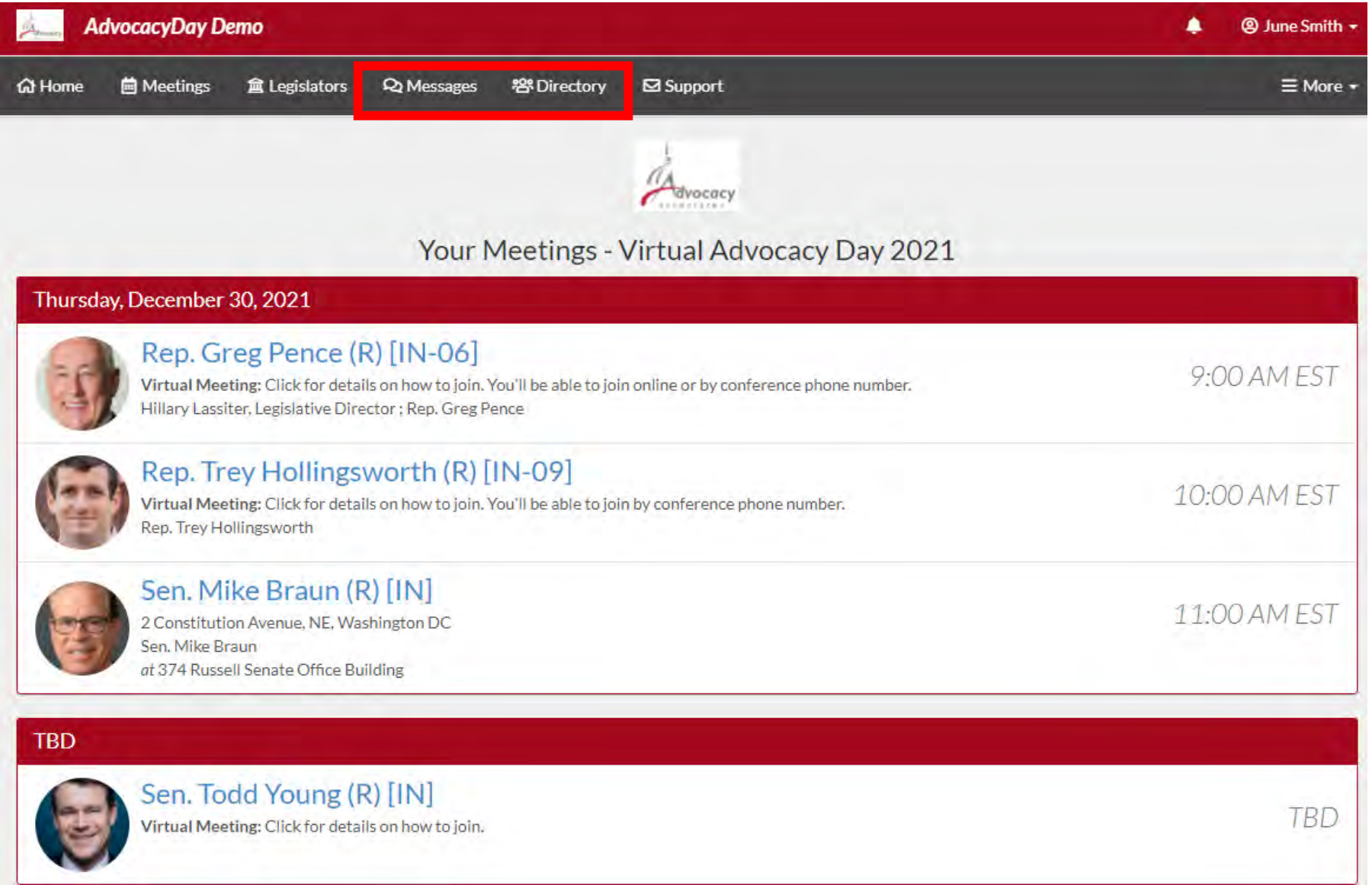
- Bio and social media contact information
- Relevant bills with voting record



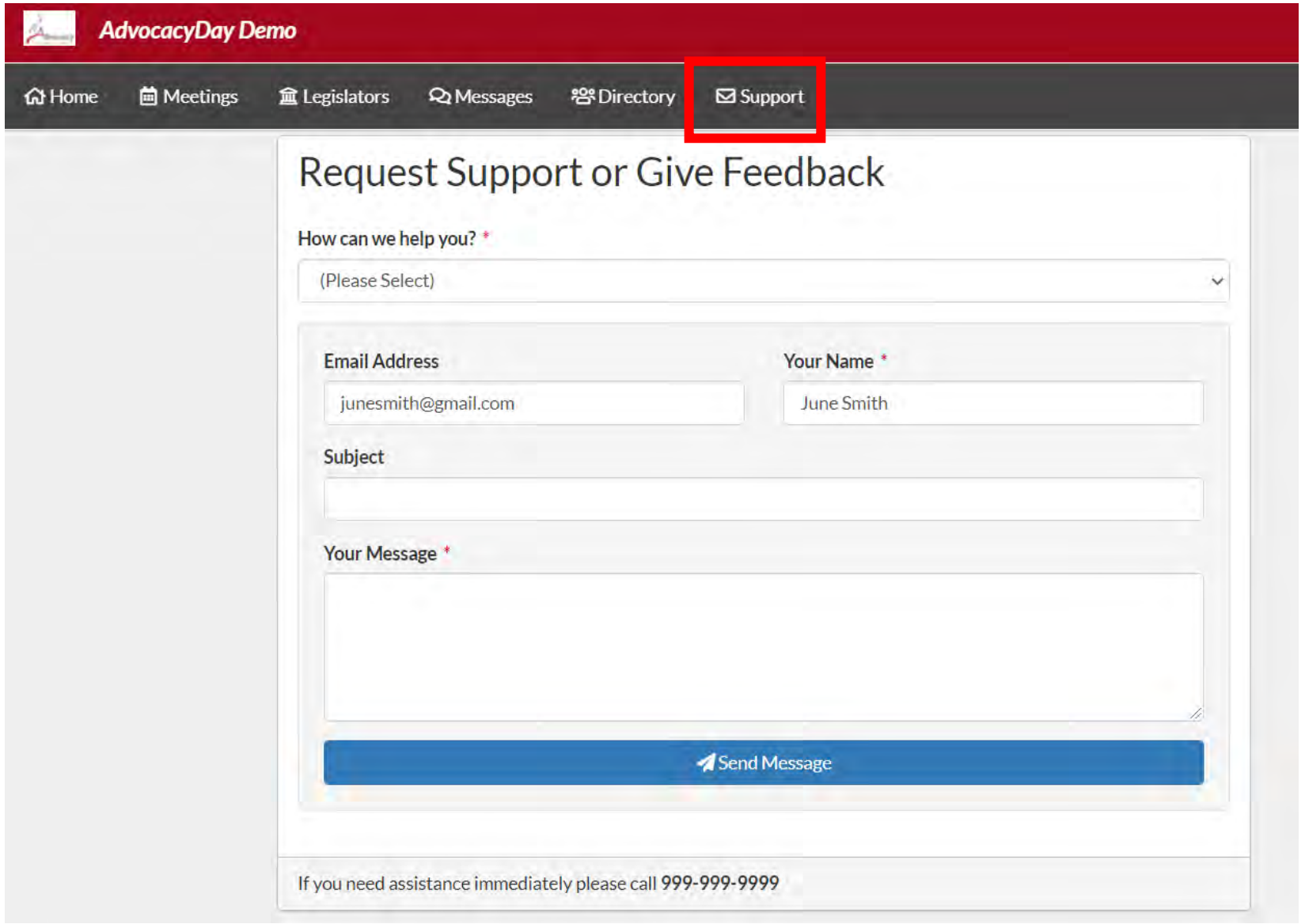
- Bio and social media contact information
- Relevant bills with voting record
- Recent news mentions



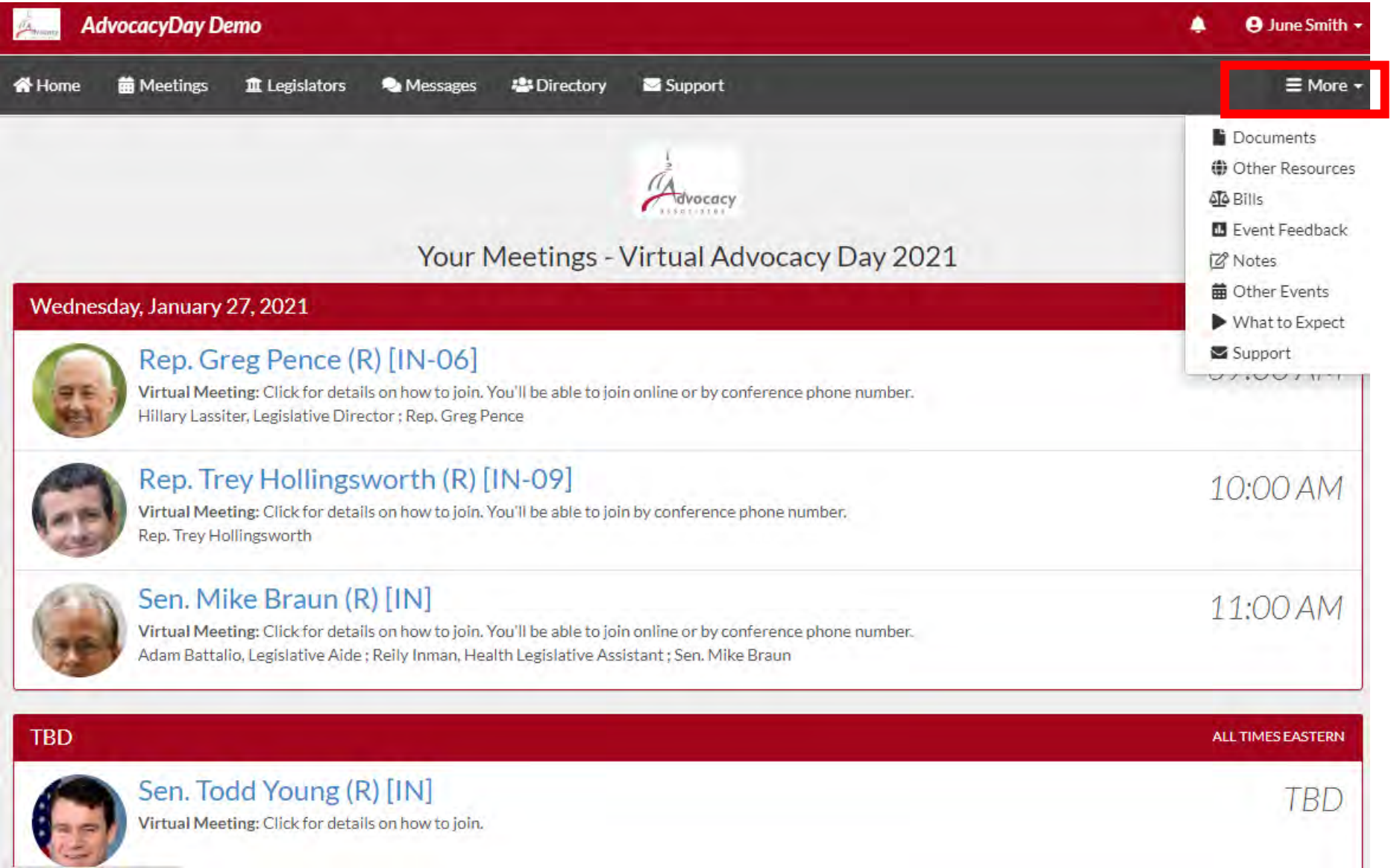
- Bio and social media contact information
- Relevant bills with voting record
- Recent news mentions
- Committee assignments



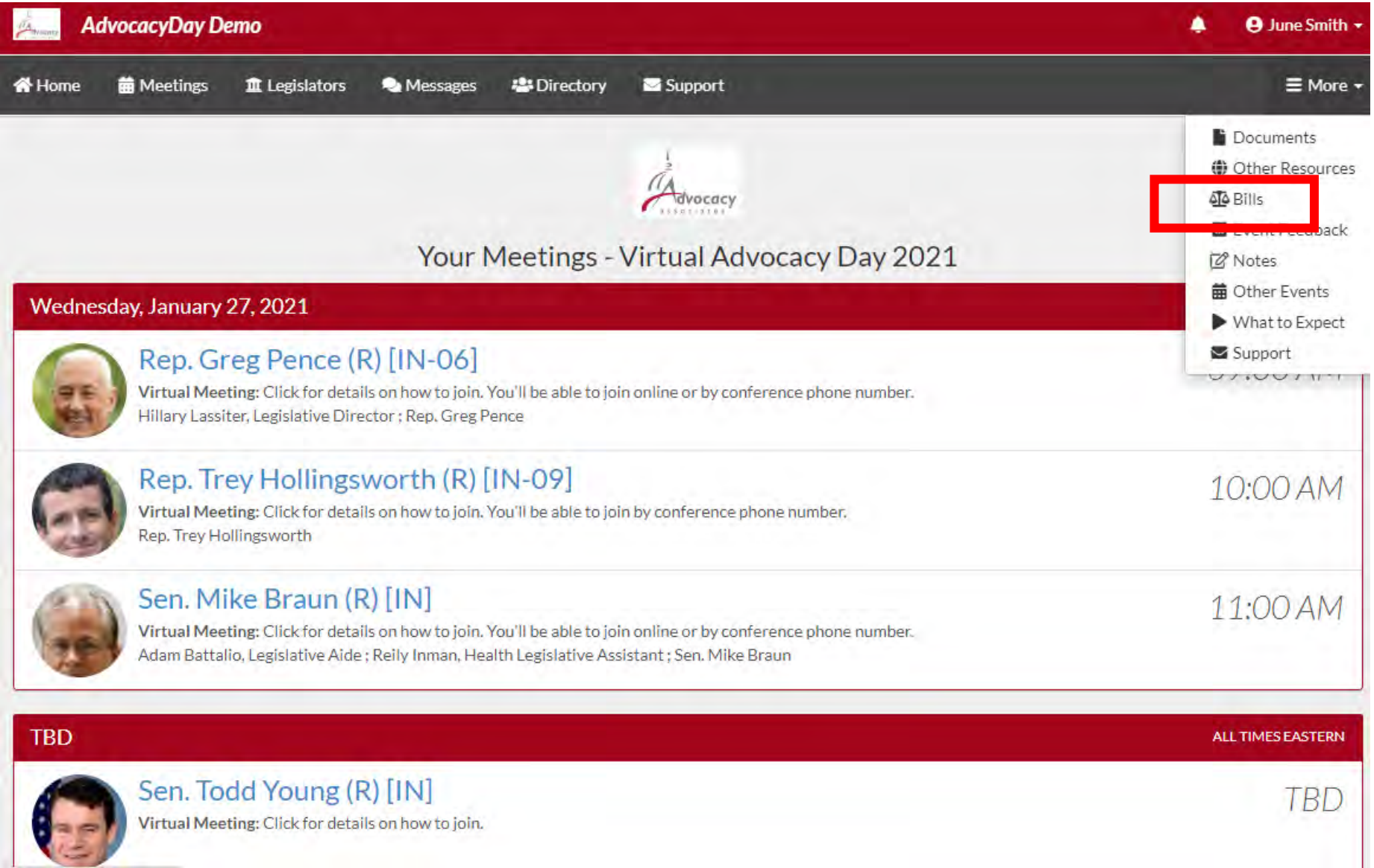
- Messages tab to access peer-to-peer messages
- Directory tab to contact any attendee in your event



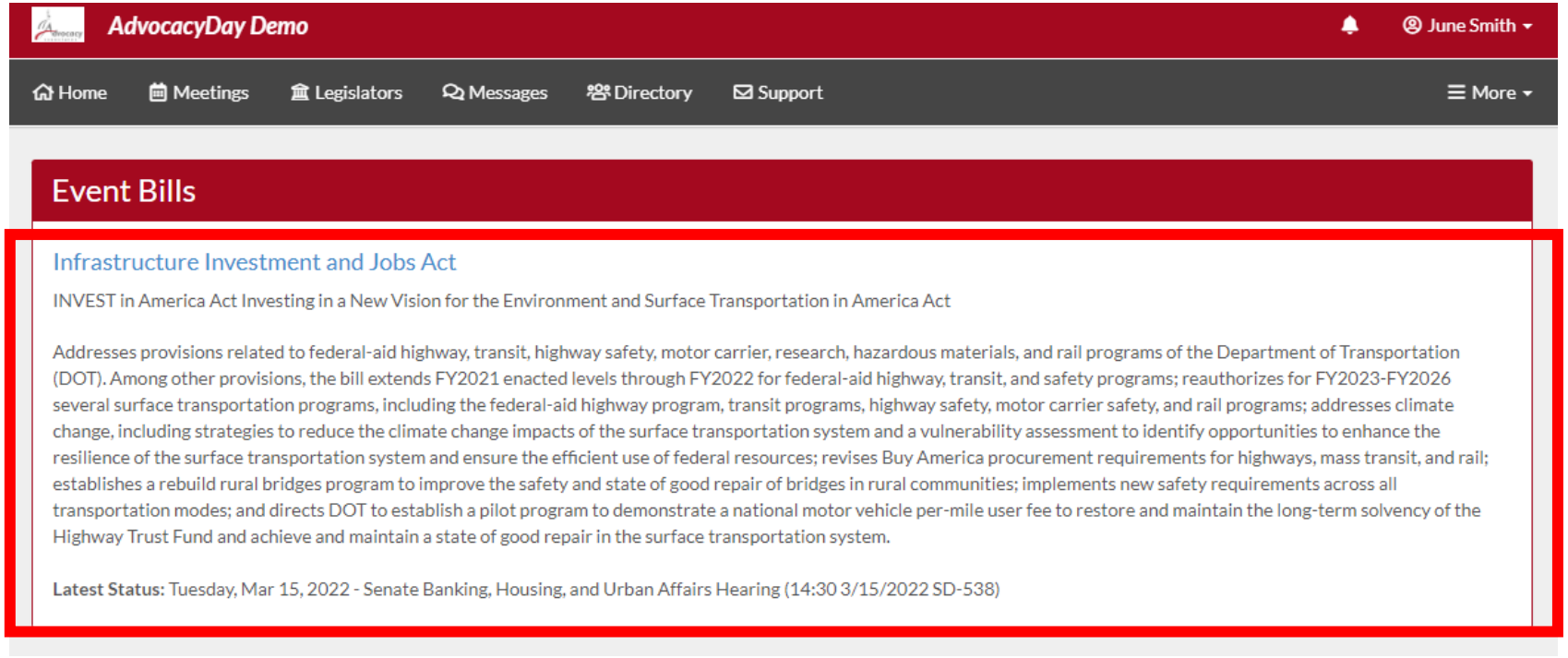
- Messages tab to access peer-to-peer messages
- Directory tab to contact any attendee in your event
- Support tab for ALL questions technical or schedule related



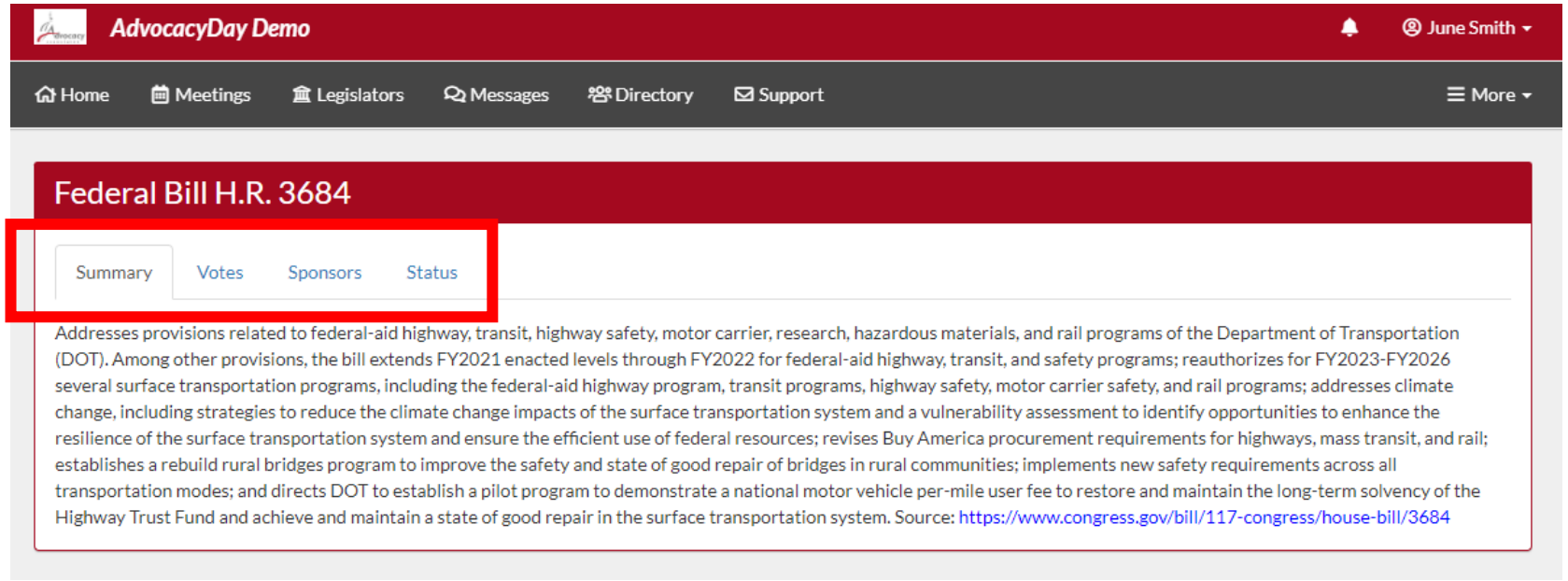
- Click the “More” tab to access additional materials, information, and resources that your organization may have provided



- Click the “More” tab
- Click “Bills”



- Click the “More” tab
- Click “Bills”
- Click on the Bill to get more information



- Click the “More” tab
- Click “Bills”
- Click on the Bill to get more information
- Summary, vote history, sponsors and co-sponsors, bill status

Relevant Information and Reminders

- Check your **SPAM/JUNK folder** to ensure you didn't miss the email with the link to your schedule (domain is @advocacyassociates.com)
- Please call/video into the meeting **10 minutes prior to the start time**, in order to discuss with your group on who will open the conversation and who will be speaking
- All times will be **shown in the time zone you are located in when viewing your schedule**
- You will receive a reminder email **1 hour prior to each meeting** from Advocacy Associates with a link to your schedule
- If the office does not join the meeting within 10 minutes past the start time, contact Advocacy Associates
- There will be a help number listed in the **Support** tab to call if you need to get ahold of Advocacy Associates
- Meetings may last anywhere from **15-30 minutes**, prepare your pitch and talking points accordingly. **ASK** how much time the office has
- Any changes to your schedule the day of the event **will be sent to you via email**. Please be sure to check regularly throughout the day
- Make sure you are in an area with a good Wi-Fi connection
- **Mute your microphone** if you are not speaking
- Know your audience - ensure you have **an appropriate background**

Online Schedules and Logistics Overview

Solve M.E.

VIRTUAL

ADVOCACY MONTH

MAY 2022

Solve M.E.
ADVOCACY MONTH

Introducing Samantha!

- Virtual Training and Event Manager
- serb@solvecfs.org
- Answer questions, adjust scheduling, send copies of training materials, and more!

Solve M.E.
ADVOCACY MONTH

Storytelling Tips

May 4, 2022

Storytelling: Do's and Don'ts

- Do be honest and authentic
- Do make it personal, it's ok to share and express emotion
- Do connect your experience to the asks
- Do repeat the asks

- Don't be negative (just the facts)
- Don't get distracted or connect to unrelated topics
- Don't make accusations/assumptions
- Don't counter or disagree with other advocates

It's ok if you don't want to share!

"I am not well enough to share today, but I stand with my fellow advocates. Please cosponsor these two important bills."

Best Practices During Your Meeting

- Be Positive
- Practice Active Listening
- Take Notes
- Ask Questions

- Correct with Kindness – *“Actually, we prefer the term…”*
- Make “eye” contact – *Look at your camera*
- Jeopardy rules – *State your asks in the form of a question*
- Remember – *You don’t have to have all the answers*
- If you lose your place – *Refer to your handout*

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Sample Meeting Outline

The Role of Group Leads

- Open the meeting
- Take Notes (or assign another note taker)
- Make sure everyone has a chance to speak (including the group lead!)
- Keep track of time, gently ask speakers to wrap up if they have gone too long
- Ask for follow-up contact information (can be at the beginning or at the end)
- Group leads are experienced advocates, able to help others
- If you are listed as a group lead, but do not wish to be, please contact Samantha (serb@solvecfs.org)

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Introductions (5-7 minutes total, 1 min per person)

The Group Lead begins the meeting when the congressional office joins the call. Invite the congressional representative(s) to introduce themselves. After they are finished, invite all advocates to introduce themselves.

Sample opening:
"Hello. Welcome everyone. Thank you so much for meeting with our group today as part of Solve M.E. Advocacy month. We'd like to share some of our experiences to show why we support these two important bills. Shall we start with introductions?"

Always include 1) Full Name, 2) City & State, 3) Your Connection

Storytelling (10-15 minutes total, 3-5 min per person)

The Group Lead calls upon each person one at a time to share their thoughts and experiences. Group Lead may remind storytellers of time limitations, if necessary. Group lead should also have an opportunity to speak.

Storytelling resources:

- Worksheet in your participant packet
- **12pm PT / 3pm ET Friday** May 6 Advocacy Café
- #MEAction Storytelling Workshop
- Training video "Meeting with Congress: A Beginners Guide" (https://youtu.be/ZhDdqSTNsLk)

Remember to include the ask to "cosponsor these two important bills"

Questions and Repeat the Request (5-7 minutes, all)

The Group Lead may conclude the meeting by answering questions, repeating our requests, and sharing contact information.

The Asks:

- **HOUSE**: Please cosponsor the TREAT Long Covid Act (HR 7482) and the COVID-19 LONGHAULERS Act (HR 2754)
- **SENATE**: Please cosponsor the CARE for Long Covid Act (S 3726) and the TREAT Long Covid Act (S 4015)

“What is the best way for us to follow up on these requests?” or “When should we reach out for an update?”

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About the Asks

May 4, 2022

“There is no question that there are a considerable number of individuals who have a post-viral syndrome …. Brain fog, fatigue, and difficulty in concentrating so this is something we really need to seriously look at because it very well might be a post-viral syndrome associated with COVID-19,”

– Dr. Anthony Fauci, July 2020

Long Covid is not new. It is the latest in a long history of illnesses triggered by infections.

Post-infection illnesses are an urgent public health crisis that requires an immediate response.

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Our Narrative

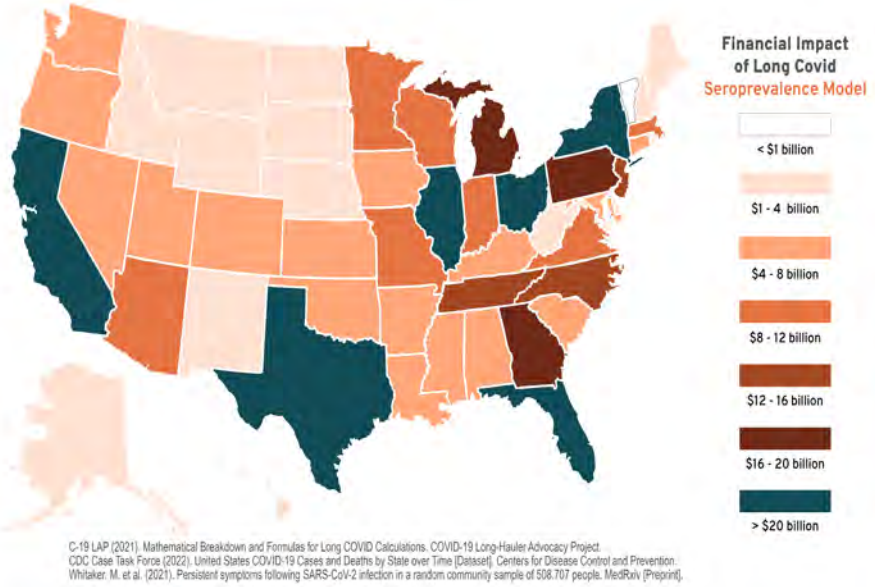
- Post-infection illness is not new. Millions suffered from “Long Haul” diseases (like ME/CFS, POTS, EDS ad more) before the pandemic

- The pandemic has caused an explosion of cases; “Long COVID” is experienced in 10-30% of infections

-Use the State tracker tool for your state and share an important fact
WWW.SOLVELONGCOVID.ORG

THANK YOU for $1.25 billion in NIH Research, but……

- NIH research takes time, we need to CARE and TREAT Long COVID NOW!



Long Covid's Impact on BIPOC communities

"The people who are likely to suffer the worst brunt of long COVID and the lack of an infrastructure to be able to deal with it are already the poorer and more marginalized communities that were hardest hit by the virus."

– Hari Sreenivasan, PBS NewsHour

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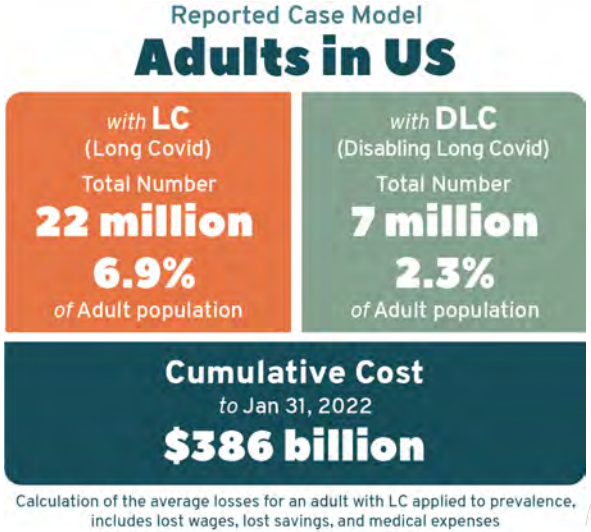
Our Talking Points

Please show your support for Long COVID by co-sponsoring CARE and TREAT

- **CARE** for Long COVID Act (S. 3726)
- **TREAT** Long COVID Act (H.R. 2754)



CARE for Long COVID (H.R. 2754 / S. 3726)

- Accelerate Long COVID research through research infrastructure;
- Educate Long COVID patients and medical providers, including information about related conditions like ME/CFS, Fibromyalgia, POTS and other forms of Dysautonomia;
- Improve understanding of long COVID treatment efficacy and disparities by expanding the Chronic Conditions Data Warehouse research database to include long COVID and related conditions
- Develop partnerships between community-based organizations, social service providers, and legal assistance providers to help individuals with long COVID access needed services.

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TREAT Long COVID (H.R. 7482 / S. 4015)

- Authorizing the Department of Health and Human Services to award grants up to $2,000,000 to health care providers, including community health centers;
- Granting funding for the creation and expansion of multidisciplinary Long COVID clinics to address the physical and mental health needs of patients;
- Prioritizing funding for health providers with expertise in other post-viral conditions;

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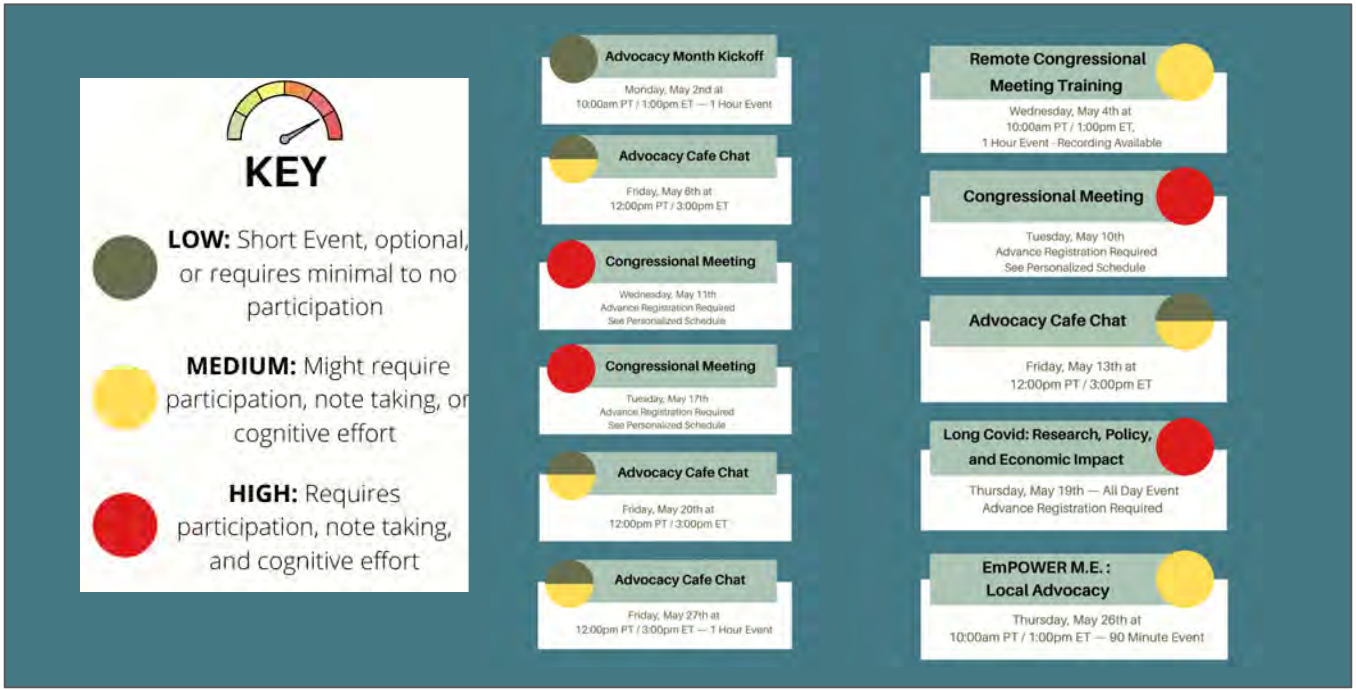
Schedule of Events

May 4, 2022

Advocacy Month Energy Guide

All events are accessible through a phone, tablet, or computer.



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Advocacy Café Chats

These weekly virtual gatherings are designed to enrich the community's experience, recap highlights of Advocacy Month, and offer an opportunity for casual and open discussion with experts.

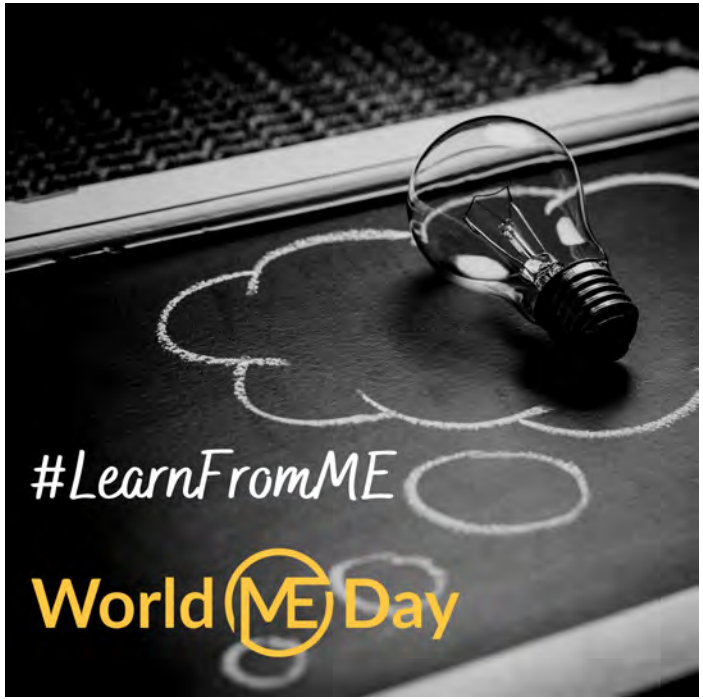
Featured Guests:
Cynthia Adinig, Solve M.E. Board Member & Person with Long Covid
Sarah Ramey, Author, *The Lady's Handbook for Her Mysterious Illness* & Person with ME/CFS and POTS
Sarah Tompkins, Ehlers-Danlos Syndrome Patient Advocate & Ms. Wheelchair Washington USA 2022

May 6, 13, 20, 27 | 12 pm PT

May 12: World ME Day

Solve M.E. is a proud member of the World ME Alliance. This May 12th, the Alliance is launching the first World ME Day and asking, “What can the world #LearnFromME?”

This year’s theme aims to highlight how people with ME/CFS and experts have a huge wealth of knowledge that could help to improve the management of this disease across the world. But even with the best management approaches that are available, there is no effective treatment or cure for ME/CFS. This is why members of the Alliance are calling for more research funding for this disease.



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Long Covid: Research, Policy and Economic Impact

In partnership with the Global Interdependence Center, this conference will explore Long COVID's long-term healthcare, policy, and economic impact.

Virtual and In-person options available.

Congressional Meeting participants receive free virtual registration. Check your email after May 17 for details.

Featured Guests:
Emily Taylor, Solve M.E.
Oved Amitay, Solve M.E.
Dr. Peter Hotez and Dr. Maria Elena Bottazzi, 2022 Nobel Peace Prize nominees

advomonth.org

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EmPOWER M.E. Roundtable: Learning from State and Local Leaders

This year, our EmPOWER ME roundtable will focus on local advocacy. They say "all politics is local." What does that mean for creating change for ME/CFS and Long Covid?

Join our panel of veteran state advocates as they discuss the importance of local and state advocacy. We'll hear about initiatives in CA, FL, MA, MD, MN, DE, and NY, and learn tips for starting projects in your neck of the woods.

May 26| 10 AM PT

EmPOWER M.E. Roundtable: Featured Speakers

Laura Bucholtz
ME/CFS Advocate
Florida State Lead

Charonda Johnson
United States Air Force Veteran,
Covid Survivors for Change
Strategic Partnerships Manager,
Delaware Advocate

Melinda Lipscomb
#MEAction Maryland State
Chapter
Co-founder and Co-Chair

Art Mirin
#MEAction California State
Chapter
Chair

Charmian Proskauer
Former President Massachusetts ME/CFS
& FM Association, Chair U.S. Action
Working Group

Suzanne Wheeler
Minnesota ME/CFS Alliance
Co-founder and President

Terri Wilder
#MEAction New York State Chapter
Co-leader

Special Thanks

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RDLA
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With gratitude to our partners:

BODY POLITIC

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C-19LAP
Advocacy, Education, Research & Support
C-19 LONGHAULER ADVOCACY PROJECT

LONG COVID FAMILIES
POST VIRAL ILLNESS SUPPORT

PATIENT-LED RESEARCH COLLABORATIVE

AMERIDISABILITY
America's Disability Community