

COVID-19 Advocacy

Responding to the Hotspots



How to Ask a Question

- Open the Q&A window
- Type your question into the Q&A box. Click **Send**
- Ask questions throughout the webinar
- Questions will be answered at the end of the webinar

Today's Speakers



Lorie Gardner
Healthlink Advocates
Chatham, NJ



Lisa Berry
Blackstock
Soul Sherpa
Los Angeles, CA



Dianne Savastano
Healthassist
Boston, MA



Lee Mulert
HealthACR
Chicago, IL



Bonnie Sheeren
Houston Health Advocacy
Houston, TX



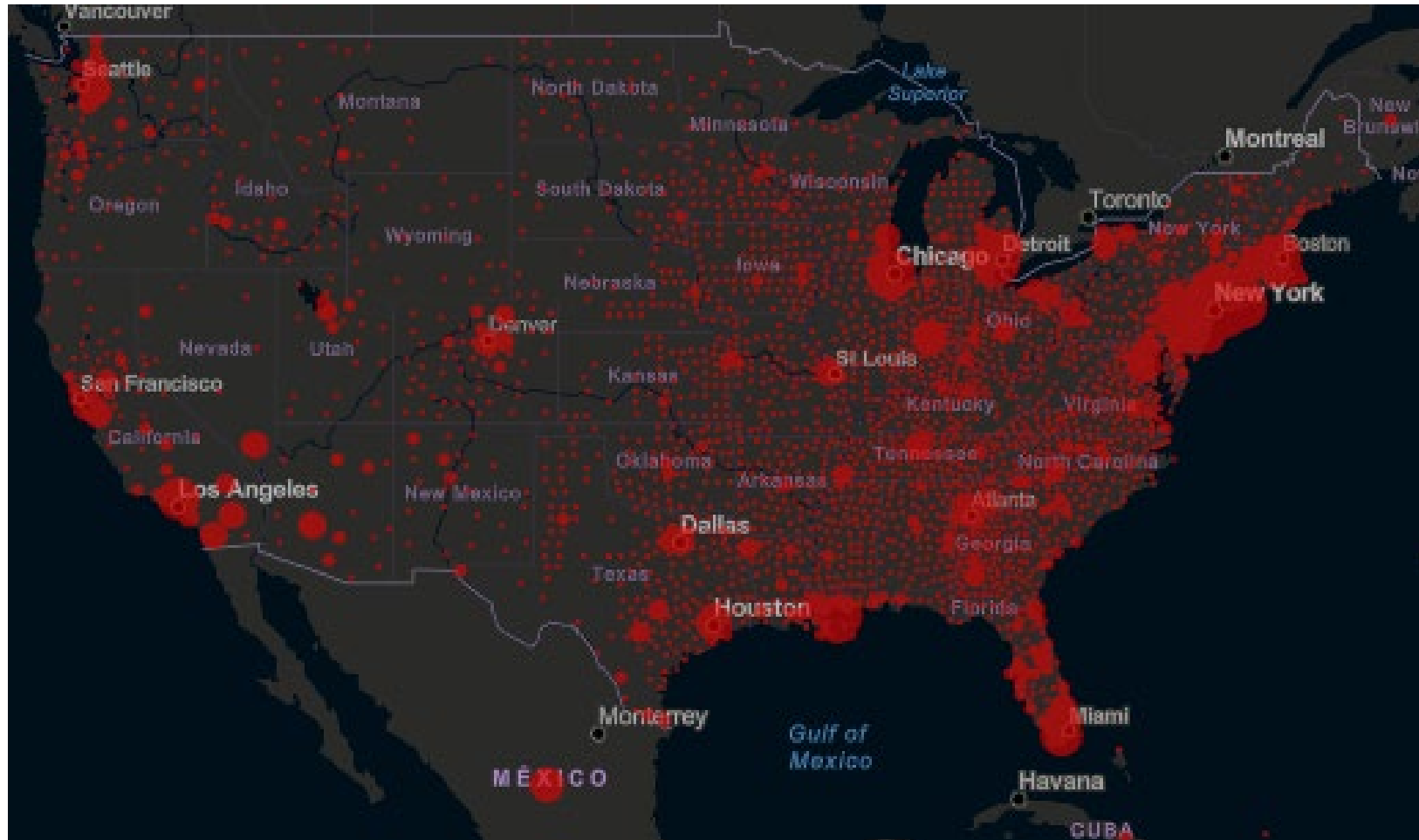
Lucille Plantemoli
Healthlink Advocates
Chatham, NJ



Io Dolka / Host
GreyZone
Seattle, WA

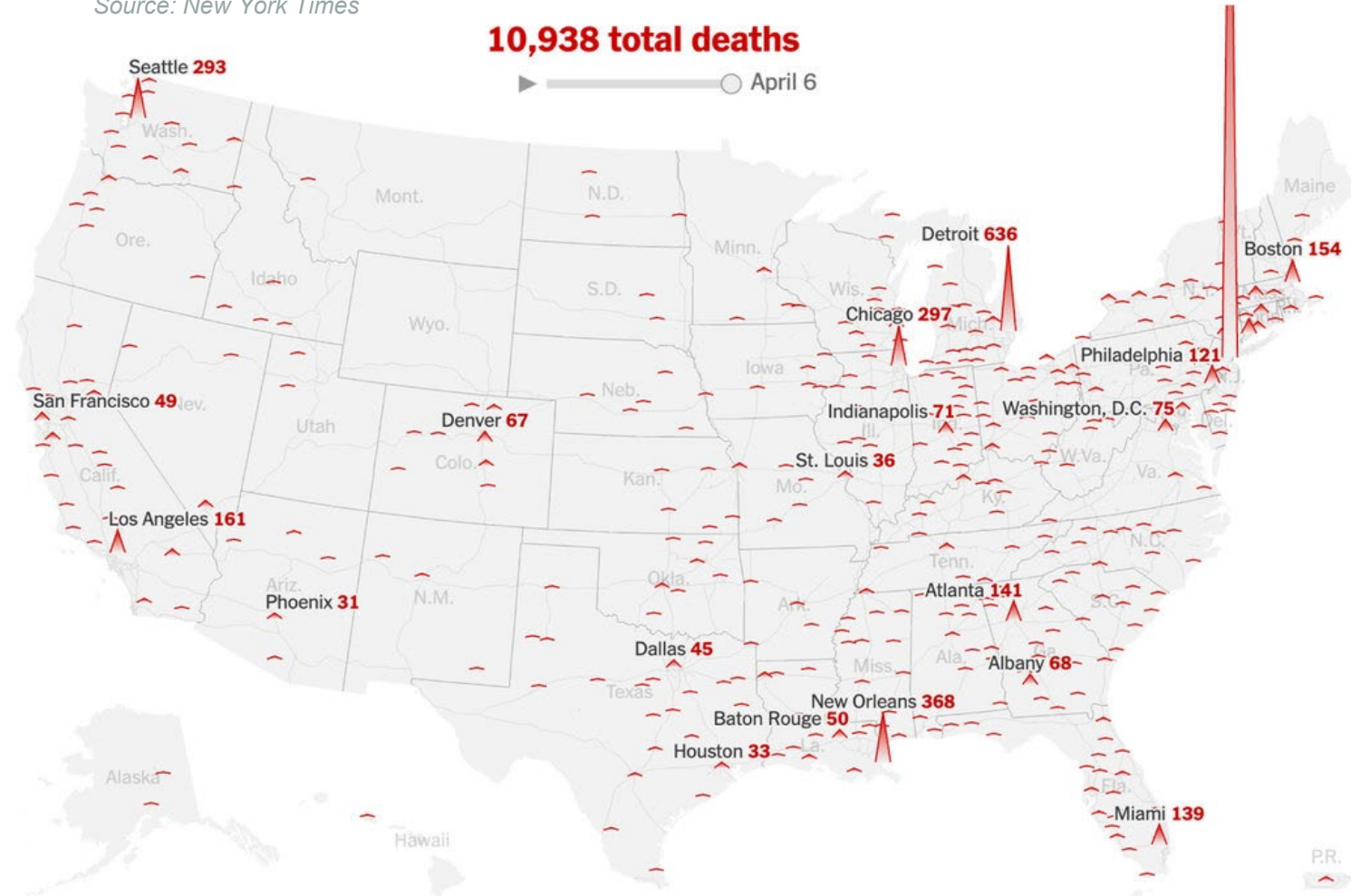
COVID-19 Hotspots

Source: Johns Hopkins University, Coronavirus Center



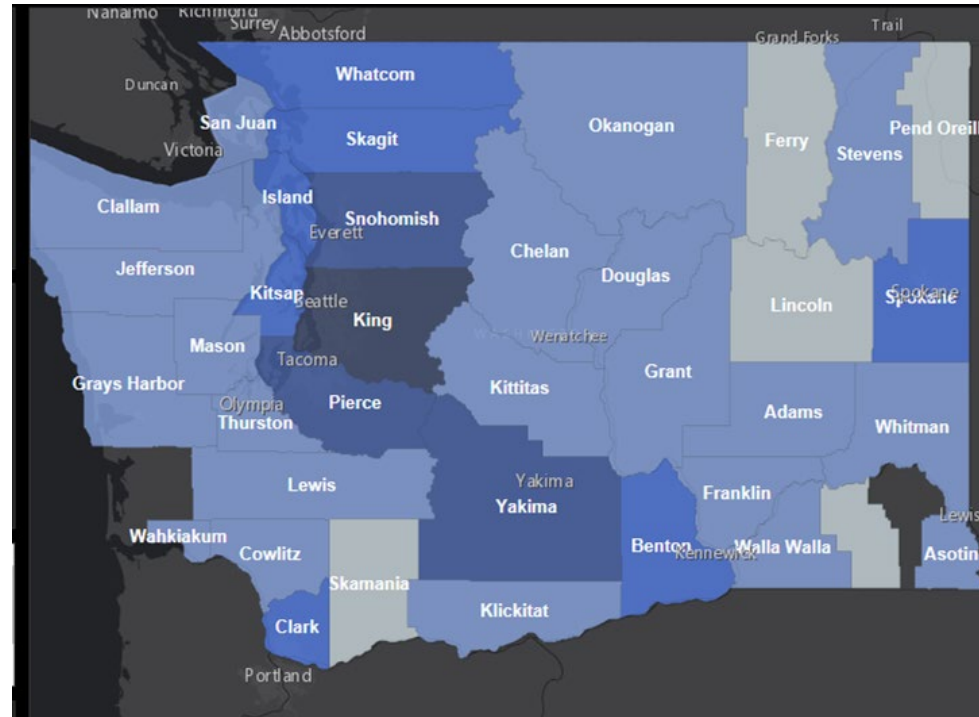
COVID-19 Fatalities by Hotspots

Source: New York Times



Washington

1st US
Case
1/20/2020



Early adopter of
strict measures

Promising results

Currently #12 State

JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
Washington	8,682	Yes, Widespread	394

Sources: Washington Department of Health, Centers for Disease Control and Prevention

© 2020 – GreyZone, LLC | Free use for non-commercial purposes only

Complex & Rare Disease Care Advocacy

Io Dolka, MS
Chief Care Advocate
GreyZone
WASHINGTON

Complex & Rare Landscape Under COVID-19

- Clients need support, some extra
- Routine/non-essential care is pushed to June or done via telemedicine
- Big diagnostic and transplant centers are still serving patients
 - Cross-state licensure and HIPAA regulations are being eased
 - Mayo Clinic uses telemedicine to see patients in their home
 - Transplant centers like UW-Madison/Mayo now do their evaluations remotely
- Medication shortages affect cancer, neurological and immune/autoimmune disease patients (ex. Plaquenil, IVIG, inhalers)
- Be ready to provide majority of advocacy services remotely

Complex & Rare Disease Care Advocacy

Io Dolka, MS
Chief Care Advocate
GreyZone
WASHINGTON

Medically Complex, Autoimmune, Rare Disease Clients

- Many are at higher risk due to:
 - Immunosuppression
 - Immunodeficiencies
 - Lung / cardiovascular, chronic disease (cancer, diabetes, AI)
- They:
 - Are afraid of getting infected
 - Need continued access to care and treatments
 - Many are also experts at facing challenges, loneliness and adversity

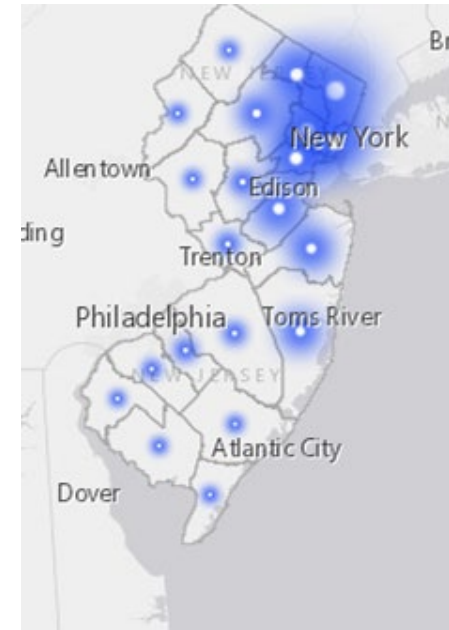
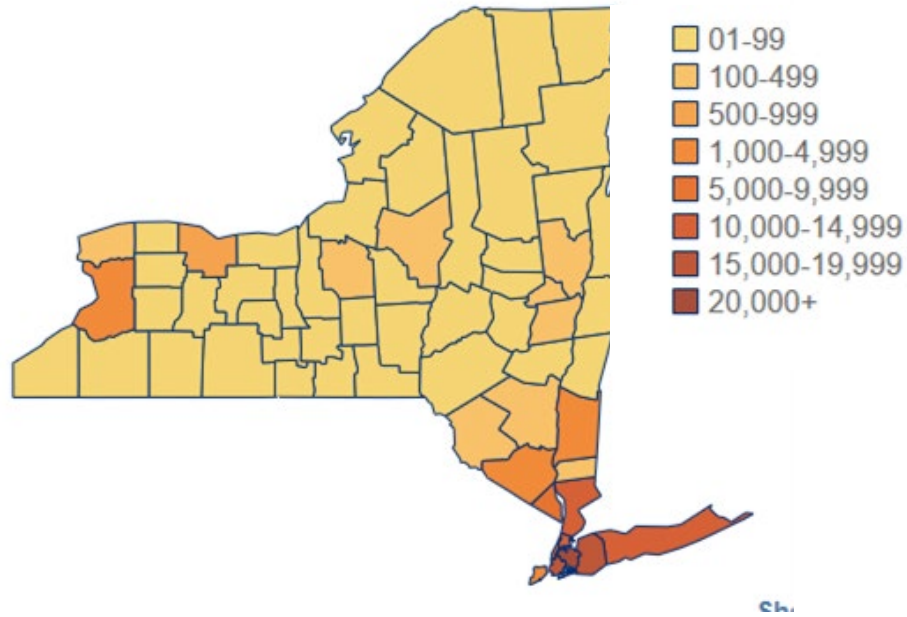
Complex & Rare Disease Care Advocacy

Io Dolka, MS
Chief Care Advocate
GreyZone
WASHINGTON

What Advocates Can Do

- Check in w complex/rare disease clients often
- Check-in w their specialists to assess risk for care/treatments
- Be proactive with regular client care plans
 - ❖ Well-controlled vs non-well controlled patients
 - Routine vs urgent care (labs, visits, procedures)
 - Medication shortages
 - Hydroxychloroquine (Plaquenil), IVIG, Inhalers, IL-1 & IL-6 & JAK antagonist biologics, etc.
 - Infusion centers vs home infusions
 - Injections (biologics, steroids, etc.)
 - ❖ Medication refills and Rx changes
 - Insurers: urged to exempt rheumatology pts from prior auth, step therapy (American College of Rheumatology)
- Plan ahead for client COVID-19 sickness (OTC medications, thermometer, etc.)
- Prepare ER Kit in case of hospitalization (Dianne)

New York & New Jersey



JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
New York	138,863	Yes, Widespread	5,489
New Jersey	44,416	Yes, Widespread	1,232

Sources: New York State Department of Health, State of New Jersey Department of Health & Centers for Disease Control and Prevention

Hospital Advocacy

Lorie Gardner, RN BSN NBC-
HWC
CEO/Founder
HealthLink Advocates
NEW YORK/NEW JERSEY

Optimize Communication to Best Serve Your Clients

- Case Study
- Intake & Hospital Stay
- Communication Plan
- Discharge Planning

Hospital Advocacy

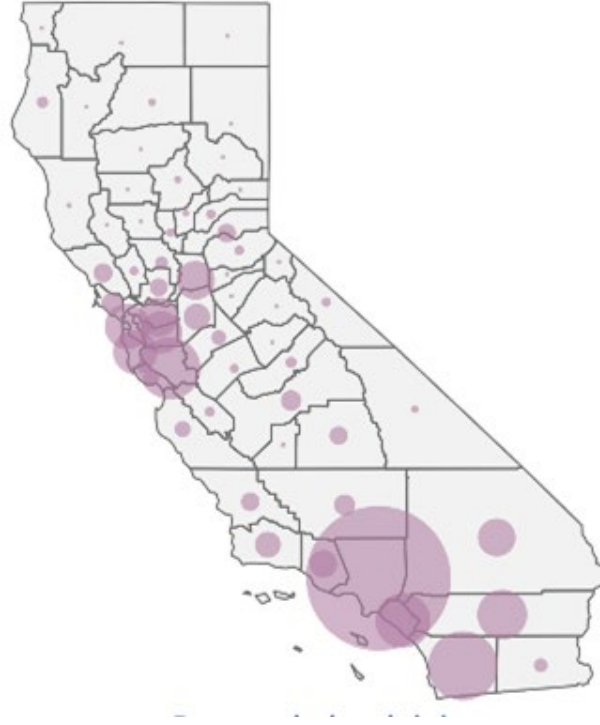
Lorie Gardner, RN BSN NBC-
HWC
CEO/Founder
HealthLink Advocates
NEW YORK/NEW JERSEY

Key Takeaways

- Be the voice of reason, calm and confidence
- A good communicator is a good listener first
- Know your clients' medical history, medication listing, physician listing, allergies and have authorizations, insurance info readily available
- Keep hospital log of all the hospital details
- Identify your "go to" person in the hospital
- Stay in close to communication with your clients' families
- **Our Mantra**
 - Think outside the box and just get it done



California



JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
California	15,865	Yes, Widespread	374

Sources: California Department of Public Health, Centers for Disease Control and Prevention

Palliative & Hospice Care

Lisa Berry Blackstock
Founder/Owner
Soul Sherpa
CALIFORNIA

Community Safety Issues During COVID-19

- Hospitals are not allowing visitors
- Safest way to transport patients with suspected COVID-19 is via paramedics

Palliative & Hospice Care

Lisa Berry Blackstock
Founder/Owner
Soul Sherpa
CALIFORNIA

Advance Life & Healthcare Planning

- Complete Advanced Health Care Directives (state specific)
- Complete HIPAA Release (state specific and possibly hospital specific)
- Complete POLST or MOLST (state specific)
 - ❖ Physician's Orders for Life Sustaining Treatment
 - ❖ Medical Orders for Life Sustaining Treatment
- All Forms are available online, search by state and/or hospital

Massachusetts & Rhode Island



JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
Massachusetts	15,202	Yes, Widespread	356
Rhode Island	1,229	Yes, Widespread	30

Sources: Commonwealth of Massachusetts Department of Health, State of Rhode Island Department of Health & Centers for Disease Control and Prevention

Community Response

Dianne Savastano
Founder & Principal
Healthassist
MASSACHUSETTS/
RHODE ISLAND

Educational Support to Change Behaviors, Problem Solving, Prevention

- Lives alone with family support
- Lives alone with no family support
- Lives in community setting

Medical Appointments

- Essential
- Medical appointments via Telehealth
- Medical appointments to postpone

Community Response

Dianne Savastano
Founder & Principal
Healthassist
MASSACHUSETTS/
RHODE ISLAND

Planning for COVID-19 Proactive Communication with Primary Care

- Symptoms, assessment regarding testing or not
- Symptom progression
- Hospitalization

Community Response

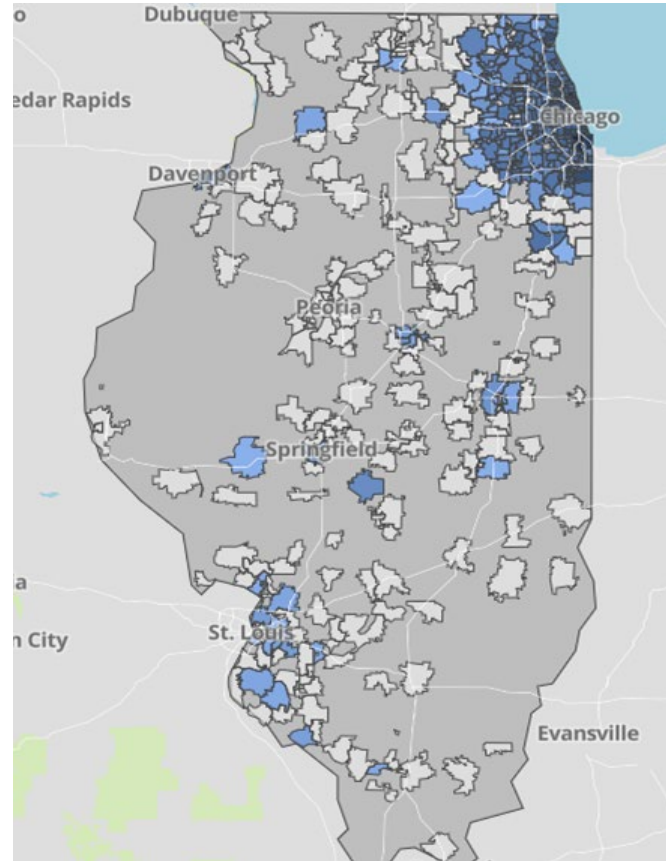
Dianne Savastano
Founder & Principal
Healthassist
MASSACHUSETTS/
RHODE ISLAND

“Grab and Go Kit” for ER/Hospital

Clients will be going alone- Share Baseline Information

- Face page with:
 - Name
 - Address and Phone Number
 - Date of Birth
 - Allergies
 - Emergency Contact Including Telephone, Email and Text
 - What you should know about John or Sally
 - Medication List
 - Medical Conditions, Past Surgeries, Past Hospitalizations
 - Current Physician List with Contact Information
 - Copy of Insurance Cards
 - HIPAA Release Forms
 - Healthcare Proxy Document
 - Healthcare Directive
 - MOLST/POLST
 - Power of Attorney
- *** Be sure a charged cell phone is available to send along with with a charger**

Illinois



JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
Illinois	13,549	Yes, Widespread	380

Sources: Illinois Department of Public Health & Centers for Disease Control and Prevention

Urgent Travel

Lee Mulert
CEO & Founder
HealthACR
ILLINOIS

What to do if Clients are in Other States or Need to Travel for Urgent Healthcare Reasons

- Current status of COVID-19
 - Where they Are
 - Impact on Them
 - Create a Plan
- Reasons for/ Degree of Urgency for Travel?
 - How will they travel?
 - Back up plans in case something goes wrong during trip
 - Emergency provisions and documents
 - What restrictions will they encounter when they get there?

Mental Health

Lee Mulert
CEO & Founder
HealthACR
ILLINOIS

Mental Health, Substance Abuse, Compulsive Disorders

- EVERYONE IS STRESSED AND ANXIOUS
 - If you already had a MH/SA disorder this just makes it worse
- Fear & Grief prominent emotions right now
- Field historically reluctant to use video or phone BUT servicing clients **right now** is crucial
 - Including the MH professionals
- Relaxed HIPAA rules have helped a lot
- Creative Approaches
- Some Hiccups
 - Zoom-Bombing of AA Meetings is extremely disturbing and disruptive

Self Care

Lee Mulert
CEO & Founder
HealthACR
ILLINOIS

Self Care for You- the Health Advocate

- **MOST Important of All**
- Just like on an airplane
- If you don't take care of yourself, you won't be good to anyone else



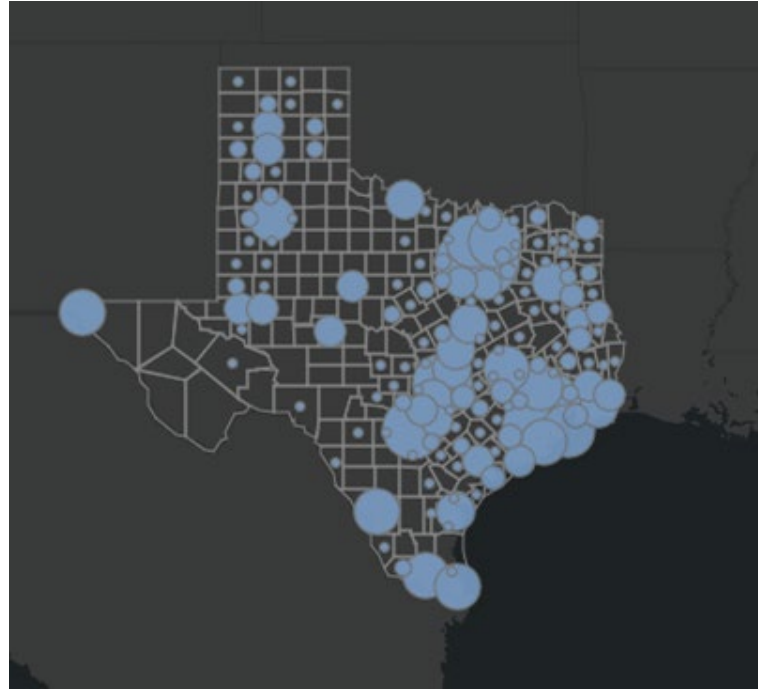
Self Care

Lee Mulert
CEO & Founder
HealthACR
ILLINOIS

Self Care for You- the Health Advocate.

- Allocate time **EVERY DAY** for self care for your mental health (helps physical too).
 - **Physical Exercise**
 - Outdoors if Possible (Vitamin D, immune system)
 - **Breath Work**
 - Yoga, Meditations, Mindfulness
 - Practice **Self Compassion**
 - **Sleep & Bedtime Routine**
 - **Talk to Others**
 - About difficult cases (maintaining confidentiality)
 - Even if it's hard to do
 - Necessary for your mental health
 - **Laughter and Music**

Texas



JURISDICTION	CASES REPORTED	COMMUNITY TRANSMISSION	TOTAL FATALITIES
Texas	8,262	Yes, Defined Areas	154

Sources: Texas Department of State Health Services & Centers for Disease Control and Prevention

Insurance Coverage & Medical Billing Planning For Clients

Bonnie Sheeren
Founder
Houston Health Advocacy
TEXAS

Insurance Coverage

- Set up access to health insurance portal to research and monitor
- Telehealth is being covered by most insurance plans including Medicare
- Coronavirus tests should be covered without cost
- Exclusionary tests (flu, strep, others) not covered
- Many insurance plans end coverage for coronavirus testing and treatment at different dates between 05/31/20-06/15/20 (No timeline for Medicare)
- Coronavirus treatment coverage varies plan to plan
- Self-funded plans coverage varies from state-regulated plans
- State-regulated plans guidelines vary from state to state, check with your state's Department of Insurance website for details

Insurance Coverage & Medical Billing Planning For Clients

Bonnie Sheeren
Founder
Houston Health Advocacy
TEXAS

Medical Billing

- Two new ICD-10 codes for Coronavirus
 - U07.1 COVID-19
 - Diagnostic code given when COVID-19 is confirmed by laboratory tests
 - U07.2 COVID-19, Virus not identified
 - Diagnostic code given for clinical or epidemiological diagnosis of COVID-19
 - Laboratory confirmation is inconclusive or not available
- Set up a patient portal with hospital for clients to monitor and document
- Monitor medical records to ensure COVID-19 diagnosis documentation to maximize health insurance coverage
- Discuss documentation with healthcare providers if possible
- Try to document out-of-network services to help with balance billing issues

Insurance Coverage & Medical Billing Planning For Clients

Bonnie Sheeren
Founder
Houston Health Advocacy
TEXAS

Treatments

- NO FDA medication treatments have been approved! Insurance will not cover experimental or clinical trials.
- Treatments range in costs and be financially costly to our clients.
- Range from reasonable to very expensive.
 - Hydroxychloroquine: \$40/50 tablets
 - lopinavir/ritonavir: \$450/dose
 - Tocilizumab IV (Actemra): \$1,177/dose
 - Plasma/Antibody Treatments: Cost Unknown
- May require urgent or external appeals to get these covered by insurance plans.

Insurance Coverage & Medical Billing Planning For Clients

Bonnie Sheeren
Founder
Houston Health Advocacy
TEXAS

Good News

- April 4, Gilead Pharmaceutical CEO announces 1.5 million doses of remdesivir at no cost for clinical trials
- Even if we do our best to document and appeal while our clients are in the hospital –there are plenty of tools to remedy insurance coverage or billing issues after our clients leave the hospital. That’s our SUPERPOWER as advocates.

Public Health

Lucille Plantemoli RN, MPH, CIC,
NBC-HWC

Vice-President

HealthLink Advocates, Inc.

NEW YORK/NEW JERSEY

Testing for SARS-CoV-2 / COVID19

Public Health

Lucille Plantemoli RN, MPH, CIC,
NBC-HWC

Vice-President

HealthLink Advocates, Inc.

NEW YORK/NEW JERSEY

Public Health Issues with COVID-19

- How to obtain a test for COVID-19 in the community
 - Department of Health
 - Primary Care Physician
- Who requires a test?
 - CDC Criteria
- State and Private Healthcare Resources
 - FEMA
 - County
 - Private

Public Health

Lucille Plantemoli RN, MPH, CIC,
NBC-HWC

Vice-President

HealthLink Advocates, Inc.

NEW YORK/NEW JERSEY

Key Takeaways for Advocates

- Be familiar with the PCPs process for testing.
- Be familiar with where testing sites are located- check the DOH website, NBC link (resources will be emailed to you).
- What to do if a client is COVID-19 positive.
 - Educate client on self-isolating guidelines
 - Separate bedroom, different bathroom, clean/disinfect all high-touch areas and surfaces, cover your cough
 - Caregiver to use PPE
 - No sharing towels, pillows, blankets
 - Wash laundry in hot water
 - Handwashing
- What to do if client is negative for COVID-19
- In summary, be prepared, informed and alert, not anxious, in order to provide the best care for your client.

Today's Speakers



Lorie Gardner
Healthlink Advocates
Chatham, NJ



Lisa Berry
Blackstock
Soul Sherpa
Los Angeles, CA



Dianne Savastano
Healthassist
Boston, MA



Lee Mulert
HealthACR
Chicago, IL



Bonnie Sheeren
Houston Health Advocacy
Houston, TX



Lucille Plantemoli
Healthlink Advocates
Chatham, NJ



Io Dolka / Host
GreyZone
Seattle, WA

Q&A

To Ask a Question

- Open the Q&A window
- Type your question into the Q&A box. Click **Send**.
- Ask questions throughout the webinar
- Questions will be answered at the end of the webinar

Q&A

Q: How are you protecting yourselves during this pandemic? Are you still meeting with new clients? How have you secured PPE for in-hospital work?

- We are practicing social distancing and following [CDC guidelines](#) in our personal and professional lives.
- Most speakers with team-based offices have transitioned to 100% work from home for every team member, with internal meetings happening virtually.
- Among the seven of us there is only one person who is physically seeing clients. The rest are meeting clients remotely for everyone's safety.
- As a certified hospice and palliative care counselor, *Lisa Berry Blackstock* received instructions concerning droplet precaution guidelines when she trained 20+ years ago. She remains current on updated PPE protocol measures and purchased her own medical grade PPE through a medical pharmacy in Los Angeles, before shortages emerged. She has been using it since March.

Q&A

Q: What's the protocol for engaging patients discharged after having the virus? Do they pose a risk for infecting others?

- *Lucille Plantemoli* notes that inpatient cases are usually discharged when they have 2 negative cultures (at least two consecutive nasopharyngeal swab specimens collected ≥ 24 hours apart).
- In general, people discharged from an emergency or inpatient unit or from an outpatient healthcare facility are instructed to self-isolate at home for at least 3 full days (72 hrs) since last having fever and without using fever-reducing medication, and since other symptoms greatly improved, and at least 7 days have passed since symptoms have first started (see [here](#)).
- *Io Dolka* also points out that the CDC [notes](#) that hospitalized and immunocompromised patients may have longer periods of when the virus is detected, and they may be infectious for longer than the average person. **Hence, these groups may be contagious for longer than others.**

Q&A

Q: I understand that patients who are on a ventilator and survive have significant health issues and a long recovery. Although this may be premature to ask, how are insurers addressing insurance coverage and continuing care?

- *Bonnie Sheeren* notes there are no federal, nationwide requirements to cover these treatments as of today. State-regulated plans (individual and group) go by each state's Department of Insurance guidelines.
- *Lee Mulert* also points out that some of the treatment approaches are continuing to evolve, which may impact insurance coverage.
- The [Kaiser Family Foundation](#) says that "while most private health plans likely cover most items and services needed to treat complications due to COVID-19, there is no clear federal requirement to do so."
- Large employer health plans are not required to cover Essential Health Benefits (EHB) that would include services such as respiratory therapy, home-delivered care, etc. Most large employers offer them, some do not.
- Bonnie also points out that this uncertainty offers advocates the opportunity to advocate for their clients to ensure coverage through any tools and tips available.

Q&A

Q: Are advanced directives (AD) being adhered to, or are doctors making decisions depending on the COVID-19 patient's prognosis?

- *Lisa Berry Blackstock* points out that to her knowledge, Advanced Directives are being adhered to as closely as possible by physicians.
- There have been extraordinary cases though, as in New York, where paramedics have been advised not to transport patients to hospitals if their likelihood of survival is grim.
- Each state has its own MOLST and POLST guidelines. In the current situation, please consult with your own state agencies for direction.
- Given family members and advocates are typically unable to be present at a loved one's bedside, physicians and hospital Ethics Committee representatives are available UPON REQUEST to make decisions with input from loved ones and advocates.
- Also, [palliative care consultations](#), if available in the hospital, could be requested to help make and assess quality of life decisions.
- *Io Dolka* also wanted to share two resources on the ethics of rationing healthcare under extraordinary circumstances. An excellent video by NUY Professor of Bioethics [Arthur Caplan, PhD](#), and the American Medical Association Journal of Ethics, COVID-19 Ethics Resource Center [page](#).

Q&A

Q: Are advocates charging for the time needed to prepare the Grab and Go Kit or any form of communication or compiling health history for clients to use?

- *Dianne Savastano answered this question during the webinar. The short answer is, yes. All of this is meticulous, time consuming, important work.*

Q&A

Q: What is the best way for an advocate to attract potential clients during this time of economic insecurity?

- *Dianne Savastano* would suggest first expanding services with **existing** clients (advanced directives, Grab & Go kits, other appropriate offerings).
- Then for attracting **new** clients we would all suggest:
 - As usual, use listings on national or local advocacy directories (PACB, APHA, NAHAC, WASHAA, etc.)
 - Work on established connections through physician offices, local programs, facilities, etc.
 - Marketing and PR through your local community. Finding ways to virtually connect to your local community and target market, to talk about relevant healthcare issues. Linking with local resources, and talking, blogging or being featured in relevant media outlets will get you in front of more people.

Q&A

Q: Does this webinar qualify for CE credits with the PACB for Board Certified Patient Advocates?

- This has been an independent, free webinar organized and provided by GreyZone, with the generous participation of the speakers. Our wish was to be a source of support and information to the advocacy community in a time of need and rapid change in the healthcare system.
- We are grateful to [PACB](#), [APHA](#), [WASHAA](#), [GNA](#) and other organizations that graciously offered to spread the word.
- On the day of the live presentation, the webinar did *not* qualify for CE credits for Board Certified Patient Advocates.
- As we appreciate the community interest in PACB CE credits, we are in discussions with PACB to explore this opportunity. We will update you by email if/when this materializes.

Additional Resources

General

- [Coronavirus Resource Center \(CDC\)](#)
- [How to Protect Yourself and Others \(CDC\)](#)
- [Medication Shortages \(FDA\)](#)
- [Autoimmune Groups Provide COVID-19 Information & Guidance \(AARDA\)](#)
- [NORD's Advice on COVID-19: You're Stronger Than You Think \(Huntington Disease News\)](#)
- [COVID-19 Testing Guide by State \(NBC News\)](#)

**Please also check links within each Q&A slide.*

Advanced Care Planning

- COVID-19 Specific Guide to Advanced Care Planning at [The Conversation Project](#), an initiative of the Institute for Healthcare Improvement.
- [COVID-19 POLST Resources](#) for healthcare professionals and patients, from the National POLST Paradigm.

Additional Resources

Self Care

- Tara Brach –psychologist, **RAIN – Recognize Allow Investigate Nurture**; many options available on free app Insight Timer or these Apple Podcasts including ones focused on coping with Pandemic:

[Tara Brach RAIN Podcasts](#)

- Kristen Neff – psychologist, concept of **Self Compassion**
[Selfcompassion.org](#)
- Coping with anxiety: [7 Science-Based Strategies for Coping With Anxiety](#)
- Helping you & your kids cope with anxiety: [Anxiety & Coping with the Coronavirus: Managing Worry - Your Kid's & Your Own](#)
- Grief: [Coronavirus Has Upended Our World. It's Ok to Grieve](#)

COVID-19 Advocacy

- Fill out Quick Survey
- Continue the Discussion on www.facebook.com/GreyZoneHealth

Questions: hello@GreyZoneHealth.com

