



DENIALS, DELAYS & DISCOURAGEMENT – Challenges in accessing health care

Presented by:

Lynne Kinst, Executive Director



WHAT IS THE BLEEDING DISORDERS COUNCIL OF CALIFORNIA (BDCC)?



Our Beginning

BDCC is a 501(c)3 nonprofit organization formed in 1985 to coordinate the shared advocacy agenda of the five California bleeding disorders organizations.



Our Focus

BDCC coordinates statewide access, education and advocacy efforts on behalf of individuals living with bleeding disorders and rare or chronic conditions.



Our Advocacy

BDCC advocates to protect access to care, promote progressive treatment options and advance the quality of life for these individuals, families and caregivers.



WHAT ARE THE
BARRIERS YOU FACE
ACCESSING HEALTH
CARE?



SOME EXAMPLES –

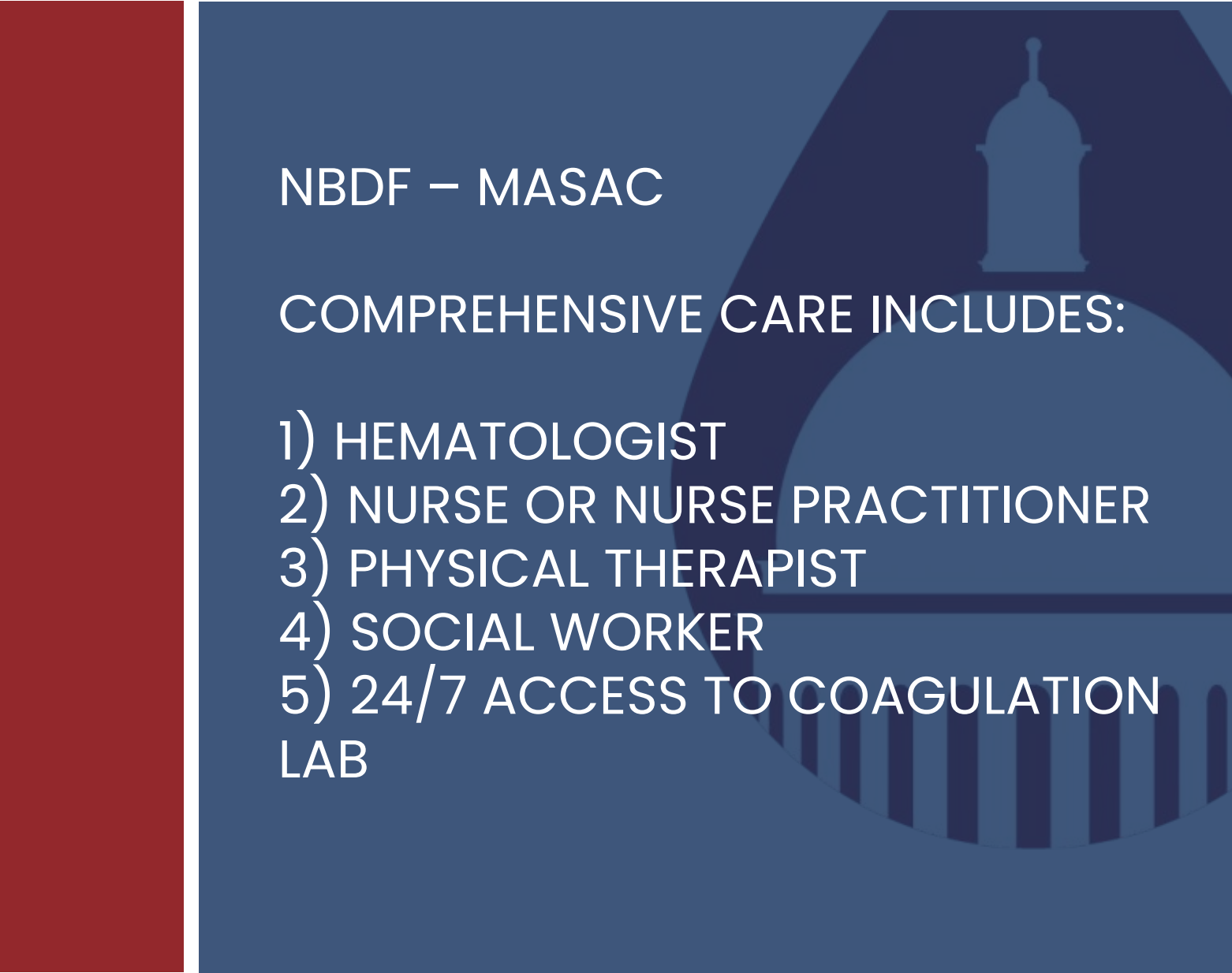
- 1) INSURANCE
- 2) PROVIDERS
- 3) DIAGNOSIS
- 4) MEDICATION
- 5) REFERRALS

Patient Story – Daniel Cruz



Patient Story – Lisandro Rios





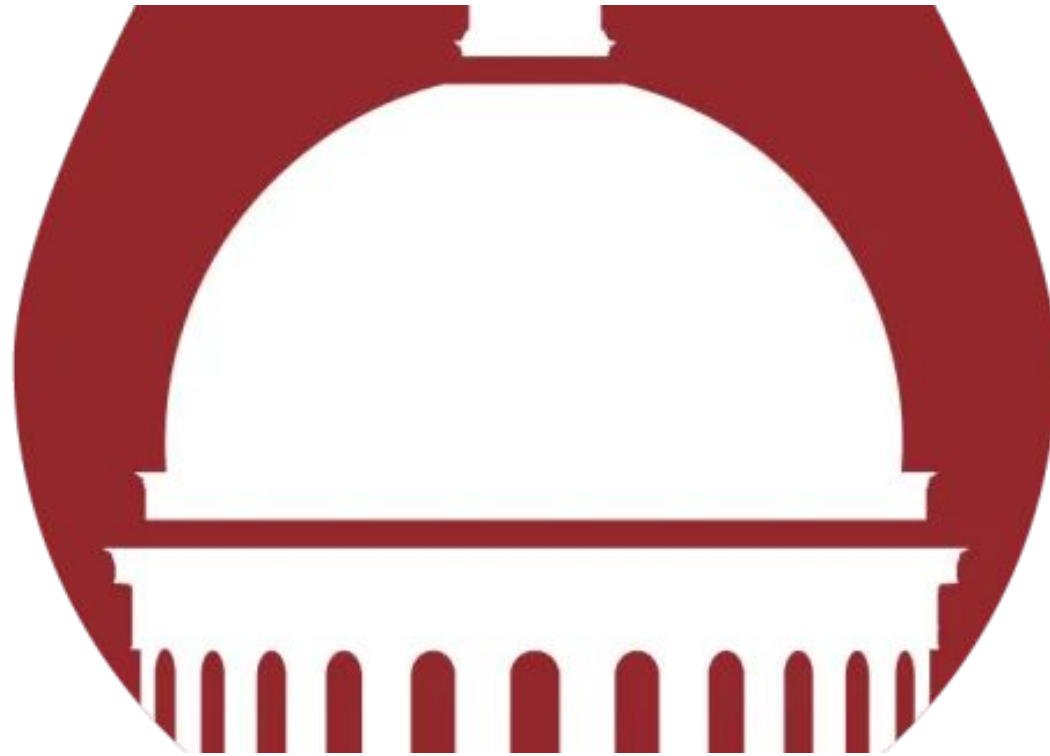
NBDF – MASAC

COMPREHENSIVE CARE INCLUDES:

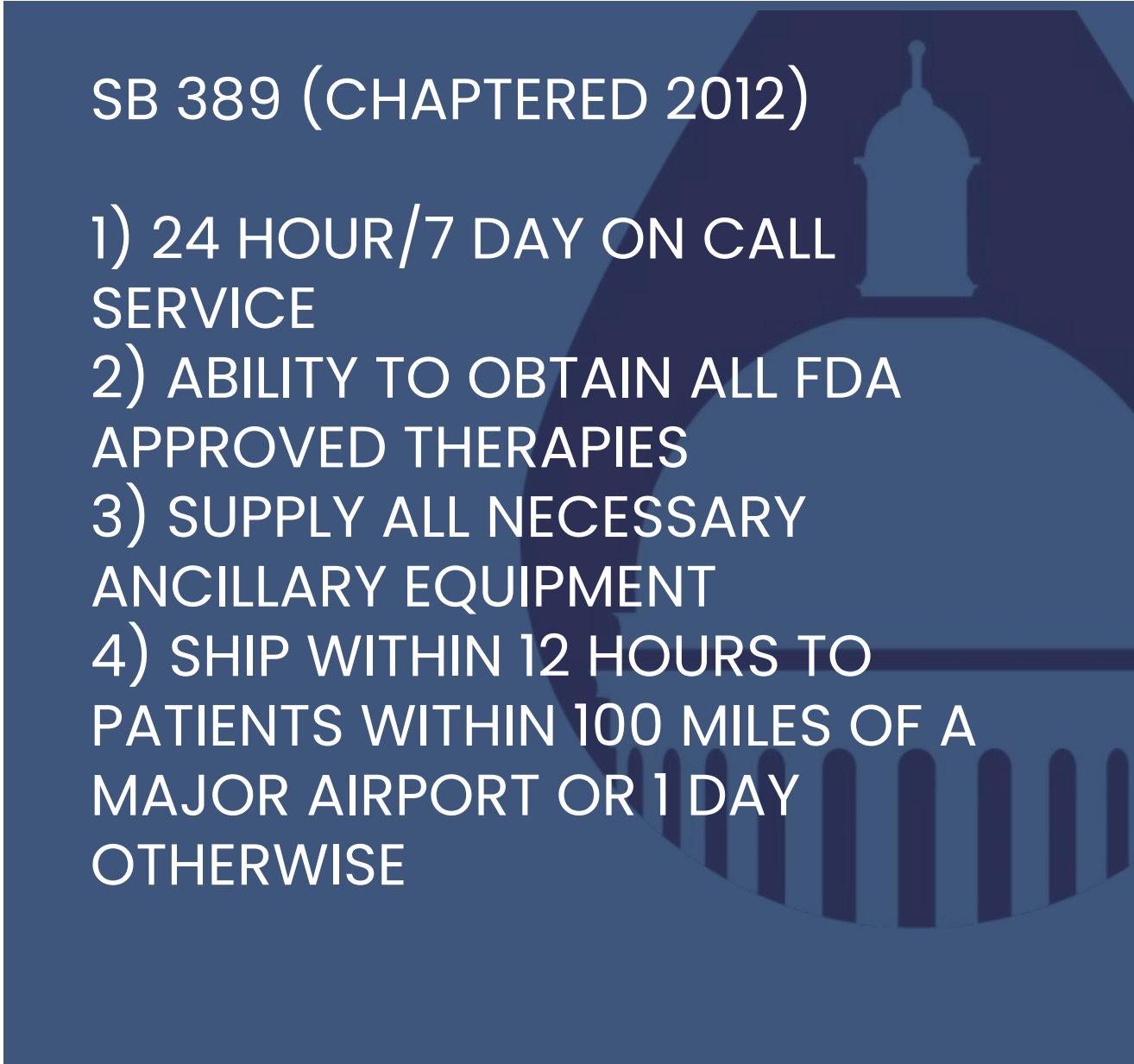
- 1) HEMATOLOGIST
- 2) NURSE OR NURSE PRACTITIONER
- 3) PHYSICAL THERAPIST
- 4) SOCIAL WORKER
- 5) 24/7 ACCESS TO COAGULATION LAB



WHAT IS THE
STANDARD OF
CARE?



ARE YOU RECEIVING COMPREHENSIVE CARE?



SB 389 (CHAPTERED 2012)

- 1) 24 HOUR/7 DAY ON CALL SERVICE
- 2) ABILITY TO OBTAIN ALL FDA APPROVED THERAPIES
- 3) SUPPLY ALL NECESSARY ANCILLARY EQUIPMENT
- 4) SHIP WITHIN 12 HOURS TO PATIENTS WITHIN 100 MILES OF A MAJOR AIRPORT OR 1 DAY OTHERWISE

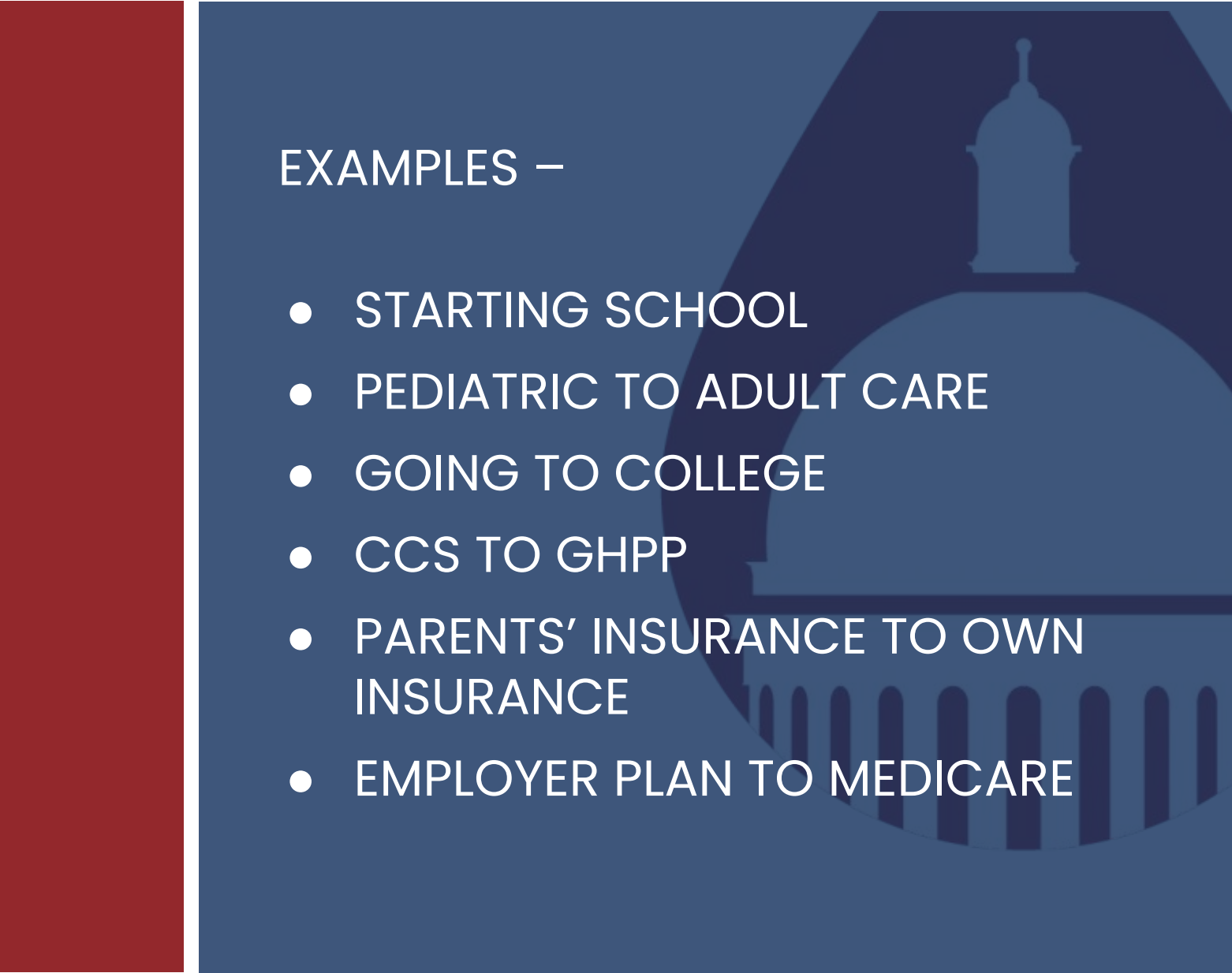


WHAT IS THE
STANDARD OF
CARE?

MEDICATION

Is your factor or non-factor
replacement product
delivered to you at home?



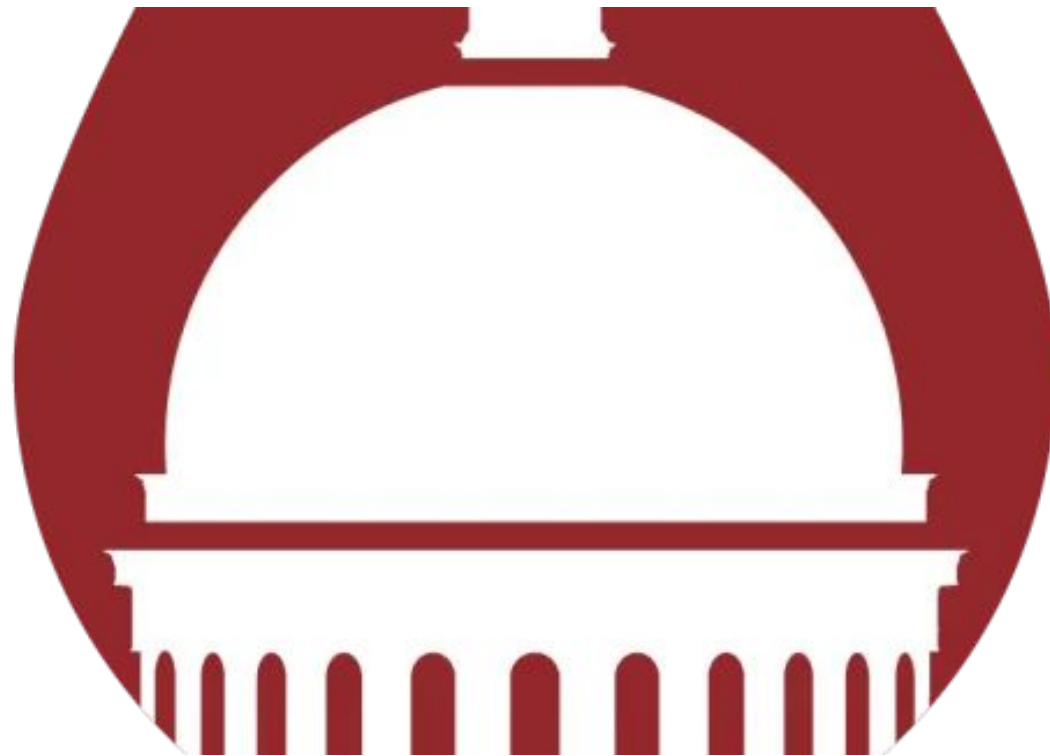


EXAMPLES –

- STARTING SCHOOL
- PEDIATRIC TO ADULT CARE
- GOING TO COLLEGE
- CCS TO GHPP
- PARENTS' INSURANCE TO OWN INSURANCE
- EMPLOYER PLAN TO MEDICARE



TRANSITIONS



WHO HELPS WITH THESE TRANSITIONS?

- 
- TALK WITH YOUR PROVIDER
 - PHONE A FRIEND
 - FILE AN APPEAL
 - FILE A COMPLAINT
 - WRITE A LEGISLATOR
 - TELL YOUR STORY



WHAT DO YOU
DO WHEN YOU
NEED HELP?

HOW TO HELP:

- Complete the Patient Health Care Survey
- Virtual Advocacy Day with the CA Rare Disease Access Coalition
- Fall Advocacy Days (October)
- Action Alerts
- Check out www.bdcouncilca.org for more!



TAKE ACTION!

Support SB 1199
(Weber-Pierson) and AB 1887
(Zbur) here in California to
protect patient assistance &
end prior authorization for
rare disease drugs.



REMEMBER –

You are your best advocate!



Overview of Upcoming Events

- May 27 – Webinar – When Distance is a Barrier to Care? Advice for visiting the Emergency Room from an ER doctor.
- May 28 – CA Rare Disease Access Coalition Meeting and Champions Reception (Sacramento)
- May TBD – Virtual CA Rare Disease Access Coalition Advocacy Day
- October – Fall Advocacy Days

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THANK YOU!

NEED HELP?

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Stay Connected!

Facebook/Twitter/Instagram - @bdcouncilca

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