

CLL SOCIETY

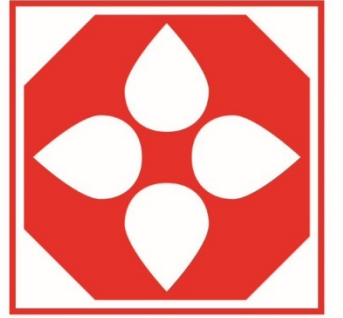
Smart Patients Get Smart Care™

Getting Maximum Benefit from Doctor Appointments

May 27, 2021

10:00 AM PT, 11:00 AM MT,
12:00 PM CT, 1:00 PM ET

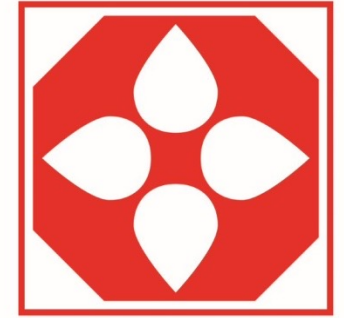
This program was made possible by grant support from



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Speakers and Agenda



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Patricia Koffman
CLL Society



Becky McAlpin, ANP-BC
UC San Diego Medical
Center



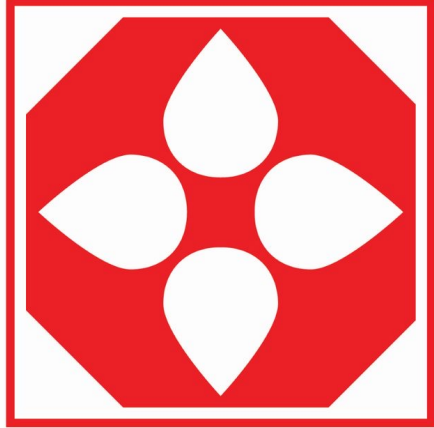
Brian Koffman
MDCM (retired) MS Ed
CLL Society



Steve Delesie
Caregiver

Agenda

1:00 PM ET	Welcome	Patricia Koffman
1:05 PM	Be Prepared: A Nurse Practitioner's Advice	Becky McAlpin
1:25 PM	Be Prepared: A Caregiver's Advice	Steve Delesie
1:45 PM	Audience Q&A	Becky McAlpin & Steve Delesie
2:10 PM	Closing Remarks	Dr. Brian Koffman



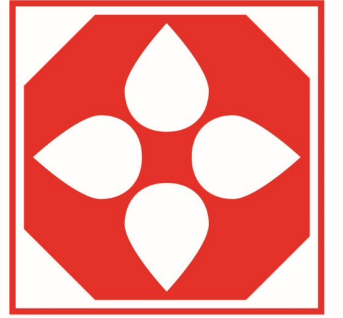
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Be Prepared: A Nurse Practitioner's Advice

Becky McAlpin ANP-BC
May 27, 2021

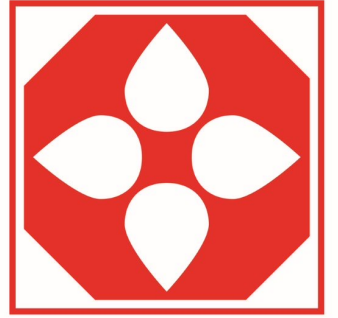
So, You Have a Clinic Visit?



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- Are you at the right place?
 - Trust yourself
 - Trust your healthcare provider
 - Trust his/her team-they are the experts!
 - Be willing to be transparent
 - Come prepared

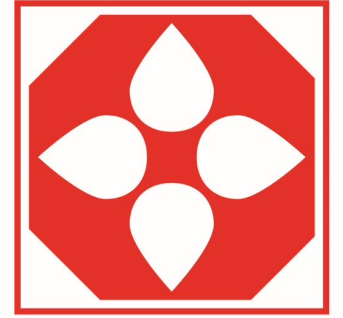
Your Visit Starts Before You Arrive



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- Prior to your visit, your healthcare team (case manager, physicians, advance practice providers, nurses and others) have already had a group meeting to discuss your appointment and make plans
- Things reviewed at the team meeting include:
 - Notes from the last visit
 - Lab results
 - Imaging (x-rays/scans)
 - Procedure results

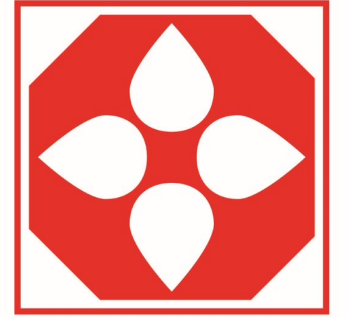
The Day of Your Appointment



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- Bring someone with you that you trust who will listen, take notes, and help keep you on track
- Consider recording the visit on your phone or other device
- Be prepared to share new information such as:
 - Insurance changes
 - Records for healthcare visits you have had since your last appointment
 - Integrative medicine visits
 - Changes in family, medical, surgical, or social history

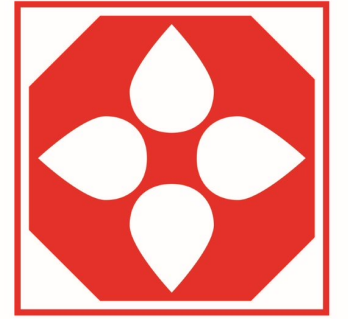
Pertinent Information to Share



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- Updated medication list
 - Any injectables and/or infusions
 - Missed doses of your scheduled medications
 - If you are on a clinical trial and are returning the study drug
- Supplements
 - When taking multiple, please bring a written list
- Change in tobacco, alcohol or other stimulants/depressants
- Travel plans

Appointment Questions



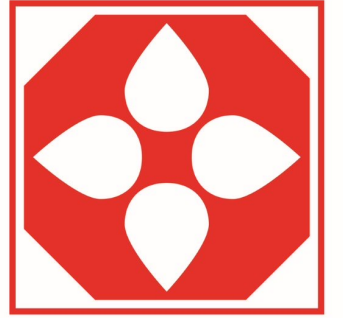
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- Prioritize questions and concerns
- If questions require education, explanation, or discussion, please limit to three



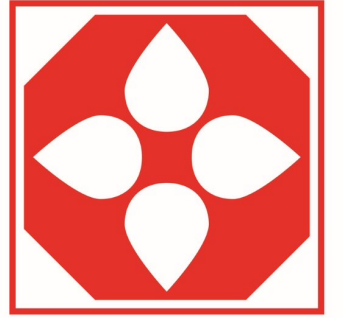
Electronic Records

- Use them to your advantage!
- Some allow patients to graph out their test results
- It can be a tool for direct communication with the staff



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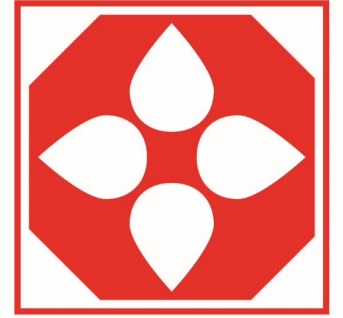
In-Person Visit or Virtual Visit



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- Virtual visits are here to stay
- If you are stable with no new or progressive symptoms and blood counts are not moving, then a virtual visit might be appropriate
- If you are having symptoms, a more thorough history and exam should take place in-person

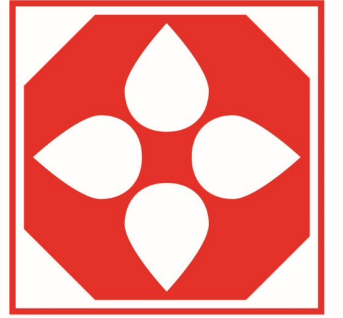
Virtual Office Visits



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- Require the same preparation as in-person visits
- The visit should take place in an area that is free from distractions
- Consider having pets cared for by others during the visit or put in a place so they don't require your care during the visit
- Have questions ready to go and have someone with you to take notes just as you would an in-person visit
- Consider where you take your camera and what can be seen

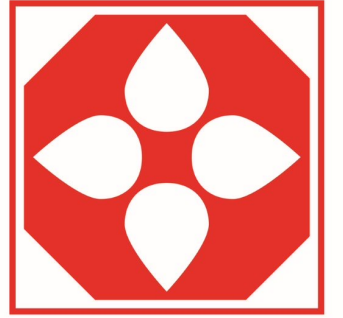
COVID-19 Protocols



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- Know what your clinic's visitor policy is before you go
- Ask ahead of time if you will need a COVID-19 test to be seen
- Make sure you share your vaccination status
- If you ask to receive the COVID-19 antibody test:
 - Be aware we have limited data
 - There are ongoing studies
 - Timetables are being made

Importance of Participating in Research

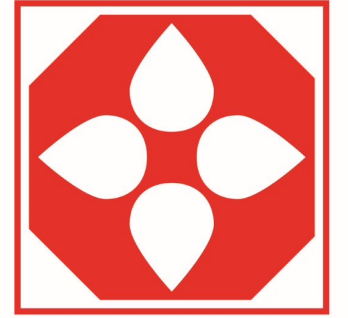


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- Please consider being a research participant
- There are research studies that only require a sample collection as a new patient and then at no more than 6 month intervals
- Research studies help scientists not only look for things for their own research, but also serve as a repository for other researchers to borrow samples from for other studies as well
- Clinical trials is our path to a cure!

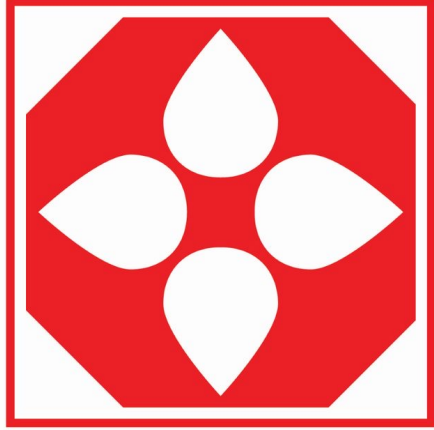
By the End of Your Office Visit

- You should feel that your most important questions were answered
- Understand what you need to do until the next visit
- Know when you should return
- Feel like the visit was an overall success



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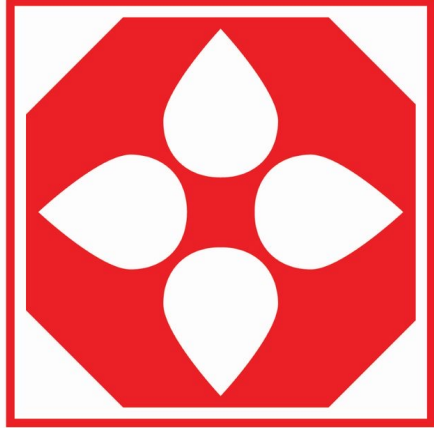




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Thank you!



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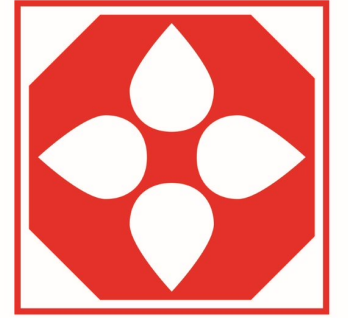
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Be Prepared: A Caregiver's Advice

Steve Delesie

May 27, 2021

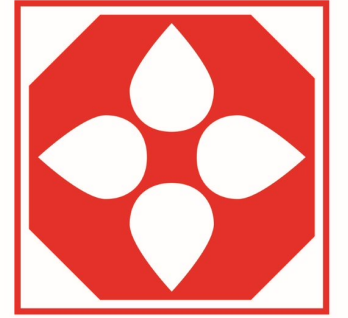
Background



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- Diagnosed by primary doctor in 2016
- Attended a CLL Society seminar at UCSD and joined the Orange County CLL Society Support Group
- Four years on Watch & Wait
- Currently taking venetoclax and obintuzumab

Advocate For Your Best Possible Care

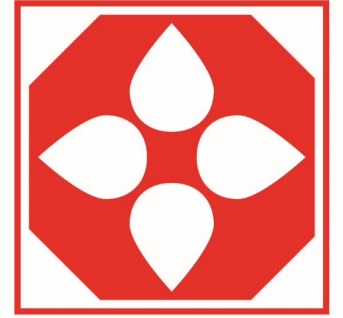


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- Learn as much as you can from the CLL Society Website (cllsociety.org)
- Join a CLL Society Support Group
- Formulate your list of questions three days prior to the appointment

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Make an Appointment Questions Form

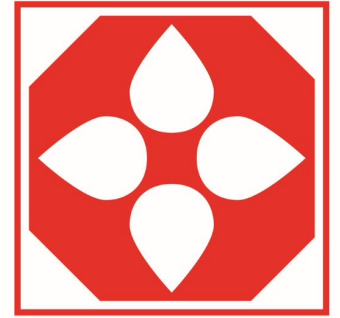


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- Include Name, Date of Birth, and Date of the Appointment
- Write down your top three most important questions in order of importance
- Include space to handwrite the responses
- Print a copy for everyone present at the appointment



Example Appointment Questions Form



CLL SOCIETY

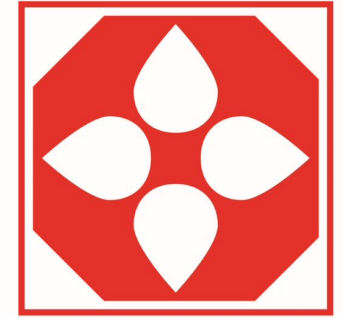
APPOINTMENT QUESTIONS

PATIENT Jane Doe **DOB** 05/05/1955

DATE 04/15/2021

- Am I still 13q deleted with no other deletions?
- Should I get a 2nd Flu Shot? 1st received on 9/15/20.
- On completion of venetoclax regimen, will you test for **MRD** in both **peripheral blood** and **bone marrow** down to **1 cell in one Million**?

CLL Events and Medical History



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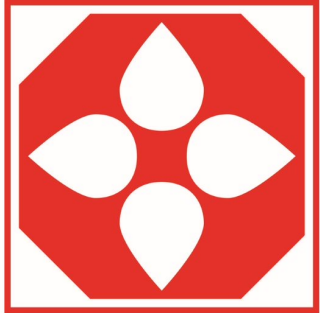
PATIENT Jane Doe **DOB** 05/05/1955

- February 2016 , Diagnosed with **CLL**
- June 2016 , Fish & Flow Cytometry **13Q Deletion**
- Sept. 2016 , IgVH, score 98 listed as **Unmutated**
- May 2019 , Bone Lesion, left femur,biopsy, result **CLL Tumor**
- June 2019 , Bone Lesion, treated with **30 Greys Radiation**
- Sept. 2019 AIHA , **Hemoglobin 4.8**, Admitted to Hospital
- Sept. 2019 Hospital, 6 days , **4 units blood & Rituximab**
- Sept. 2019 Infusions **600ml Rituximab** for four weeks

- List out your *major* events in chronological order in case your physician does not have immediate access to your history
- It's a good practice to keep this list handy when you travel

Keeping Track of Lab Results

Where to find the Holy Grail of Your Personal Lab History!



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⚡ Chronic Lymphocytic Leukemia Toolbox

Abbreviations & Acronyms

Ask The Doctor

Ask The Pharmacist

Ask The Laboratory Scientist

Ask the Palliative Care/Hospice Doctor

Ask the RN

Build-A-Team

CLL Doctors

CLL Glossary

CLL Links

Keeping Track Of Lab Results

Normal Lab Values

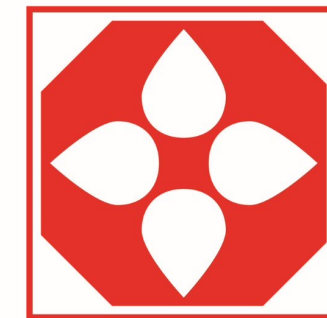


Download Template



How to use the Keeping Track Patient Records Spreadsheet

Example Lab Tracking Form



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Jane Doe



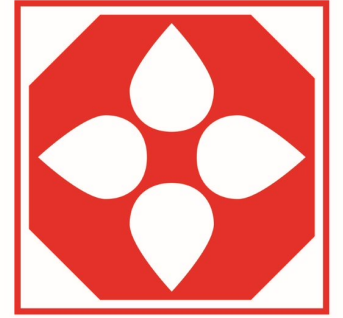
Click on a ?
for additional help information

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CBC Information

Date	WBC	RBC	HGB	HCT	Platelets	Percent Lymphs	Absolute Lymphs	Percent Neuts	Absolute Neuts	MCV	MCH	MCHC	RDW	MPV	NOTES
?	?	?	?	?	?	?	?	?	?	?	?	?	?	?	?
Range=>	3.5-10.5	4.2-6.1	12.1-17.2	36-50	150-450	28-55%	0.85-4.1	25-70%	1.5-7.8	80-100	28-32	32-36	11%-15%	7.5-11.5	
1/1/15	5.5	4.2	12.1	36.0	150.0	28.0%	0.85	25.0%	1.5	80.0	28.0	32.0	11.0%	7.5	
5/1/15	6.0	7.0	18.0	50.0	154.0	60.0%	0.90	26.0%	3.0	82.0	33.0	37.0	20.0%	11.0	
1/1/16	7.6	6.0	15.0	45.0	170.0	40.0%	0.95	25.0%	4.2	81.5	28.0	32.0	11.0%	7.5	
5/1/16	5.5	4.2	12.1	36.0	155.0	28.0%	1	25.0%	3.0	81.0	33.0	37.0	11.0%	8.4	
1/1/17	11.0	7.0	18.0	50.0	160.0	60.0%	0.9	27.0%	1.5	80.0	28.0	34.3	12.0%	8.5	
5/1/17	9.0	6.0	15.0	45.0	220.0	40.0%	2.00	26.0%	2.0	82.0	33.2	36.0	13.4%	9.2	
1/1/18	5.5	4.2	12.1	36.0	235.0	28.0%	2.15	28.0%	3.2	83.0	28.0	42.0	11.0%	7.5	
5/1/18	11.0	7.0	18.0	50.0	215.0	60.0%	3.10	30.0%	3.4	84.5	33.1	35.7	14.0%	8.8	
1/1/19	9.0	6.0	15.0	45.0	320.0	40.0%	3.15	31.0%	4.4	92.0	32.4	37.3	12.4%	9.2	
5/1/19	5.5	4.2	12.1	36.0	220.0	28.0%	2.99	32.0%	4.2	81.0	33.0	34.0	13.2%	9.9	
5/1/20	11.0	7.0	18.0	50.0	245.0	60.0%	4.10	28.5%	5.0	84.2	31.2	33.4	14.5%	7.6	
7/1/20	9.0	6.0	15.0	45.0	260.0	40.0%	3.99	33.0%	5.1	82.0	29.4	33.0	12.2%	8.2	

Why You Should Use the Lab Results Tracker



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LAB RESULTS

Enter or View CBC Values

Select

View CBC Charts

Select

Enter or View Blood Chemistry Values

Select

Enter or View Immunoglobulin Levels

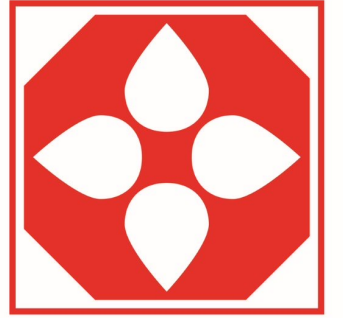
Select

- In case your doctor does not have immediate access to your lab history
- Allows for a broader view of your long-term *trending* history for all key CLL lab components (CBC, Absolute Lymphocytes, and more)
- May be useful if you need an urgent care or emergency room visit where they don't have access to your healthcare providers

Takeaways

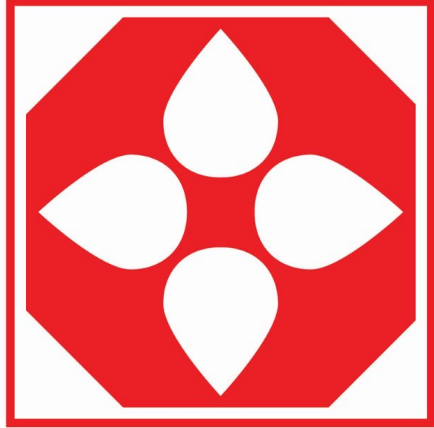
There are three things you can do to help you always be prepared

- Make a list of your questions prior to your appointments
- Keep track of your key CLL events and Medical History
- Utilize the CLL Society's Lab Tracking Spreadsheet



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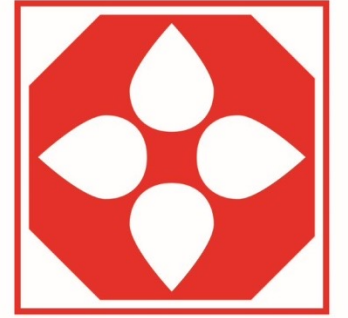




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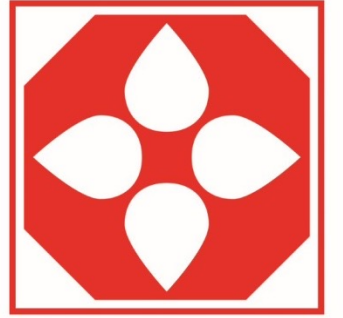
Thank You!



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Audience Questions & Answers

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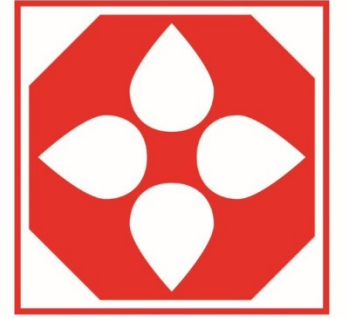


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Adaptive
biotechnologies™

 **Bristol Myers Squibb™**

Thank You for Attending!



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Please take a moment to complete our **post-event survey**, your feedback is important to us

Join us for **Learning to Decode Your Blood Test Results for CLL** taking place on Tuesday, June 29

CLL Society is invested in your long life. Please invest in the long life of the CLL Society by supporting our work

cllsociety.org/donate-to-cll-society/