



ICBCC Campaign 2022

Interim Report

#ConsiderTheCompromised #ICBCC



ICBCC

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Preface & Introduction

This interim report summarises the activities to date carried out by Patvocates and the secretariat of the CLL Advocates Network to build an international coalition of representatives from the global patient advocacy and clinical community, set up to promote the needs of immunocompromised patients around the world in the face of the ongoing COVID-19 pandemic: the [International Covid-19 Blood Cancer Coalition \(ICBCC\)](#).

Recognising the urgent peril these IC people have been facing and continue to face daily and to varying degrees, and in different parts of the world, the CLL Advocates Network, by making use of its vast international network of patient organisations and researchers in the field of blood cancer, together with Patvocates, a consultancy in the area of patient advocacy and patient engagement, and with the support of well-known patient organisations, researchers and clinicians in the haematological area, published a [manifesto](#) in early 2022, outlining core demands and recommendations to protect the lives of those who cannot do so for themselves.

Addressing three stakeholders – policy makers, clinicians and the public – the Coalition has since conducted a four-day online campaign, disseminating tailored Social Media toolkits and content on- and offline, and has made an appearance at various congresses and events in the field of haematology. The ICBCC campaign, conceived as an ongoing social and political endeavour and call to action, urges all stakeholders to take the needs of aforementioned immunocompromised patients into consideration according to their areas of influence.

In the following, this interim report will describe in detail the rationale behind the ICBCC Campaign, what specific and concrete actions can and need to be undertaken to protect the lives of immunocompromised (IC) people and what has been achieved so far.



1. Rationale behind the ICBCC campaign

The estimated share of those who are immunocompromised (IC) is between two and three percent of the total global population. These people are more vulnerable to contracting and suffering poor outcomes with COVID-19. During the last two and a half years their circumstances have been neglected to varying degrees, with significant disparities by geographical location.

The antibody response of said people to COVID-19 vaccines, including booster shots, have been repeatedly proven less predictable and robust when compared to the general population. Yet, there is evidence that booster shots do yield benefits for people living with hematologic malignancies.

What is known is that immunocompromised (IC) patients in general, and blood cancer patients in particular, have:

1. A much greater risk from COVID-19 including higher rates of hospitalisation, ICU admissions and death.
2. Higher rates of breakthrough infections after being fully vaccinated.
3. Higher rates of their infection spreading from household contacts.
4. No simple lab test to reliably predict protection post vaccination.
5. Shown in some cases to carry and shed severe acute respiratory syndrome coronavirus (or SARS-CoV-2) for months leading to the risk of introducing potentially dangerous new mutations into the broader population.

While about 97% of the adult population has the option of a safe and effective way to prevent a severe COVID-19 disease course and can re-engage in the world by getting vaccinated, the vulnerable 2 to 3%, namely IC patients, continue to be cautioned by local and global health authorities not to rely on vaccines for protection.



2. Formation of the International COVID-19 Blood Cancer Coalition (ICBCC)

For the reasons mentioned above and to address the specific impact of the pandemic on immunocompromised blood cancer patients (both acute and chronic), and to recommend solutions and actions to mitigate those risks, a multi-stakeholder consortium consisting of representatives from the global patient advocacy and clinical community has formed the [International COVID-19 Blood Cancer Coalition \(ICBCC\)](#), with [the CLL Advocates Network \(CLLAN\)](#) acting as the secretariat on behalf of the coalition.

To aid with advocating for the provision of anti-COVID-19 treatment and care for immunocompromised (IC) blood cancer patients, the coalition has prepared a [Joint Patient Impact Statement](#).

3. Central considerations and principles of the campaign (see [Patient Impact Statement](#))

The mantra of “*Get vaccinated, but act as if you are not*” is an appropriate interim solution. However, IC patients should not be expected to remain locked down indefinitely as the rest of the world returns to near normal. The special vulnerability of those with blood cancers and others needs to be addressed in a proactive way. Although one must be prepared for surprises when dealing with COVID-19, certain principles can guide best practices for the IC community:

1. There is public fatigue with health measures.
2. Public awareness of issues for IC is important.
3. IC blood cancer patients must be included in the priority treatment groups with those considered at high risk and most vulnerable to COVID-19 infection. Everyone, regardless of their immune status, should be vaccinated. The active immunity from a vaccine is preferred for those who can rely on it. The more people are vaccinated, including booster vaccine doses, the more the IC are protected.
4. Strategies and actions for IC need to rely on post-exposure antivirals and pre-exposure COVID-19 monoclonal antibodies (CmAbs).
5. Educating the IC patients that continued masking and social distancing in high-risk circumstances are essential even if the public rules on masking and social distancing are relaxed. This is especially true in settings where the IC will likely be present such as during public transit and in public buildings.
6. Safety measures and masking should continue to be maintained in any clinical setting when treating IC patients even when public rules are being relaxed.



4. Core demands and recommendations of the ICBCC campaign (see [Patient Impact Statement](#))

Based on the above analysis, the coalition has formulated the following key demands and recommendations:

1. Access to fast response COVID-19 testing for high-risk patients. Many of the lifesaving therapies must be instituted quickly after diagnosis to be effective. Waiting a week for the results of a PCR test could be a fatal delay. Possible solutions include:
 1. Special access to home tests for the IC community.
 2. Testing slots set aside or special testing sites for the IC.
 3. Systems should be in place at national level to process the IC that test positive to COVID-19 to ensure a quick access to treatment.
2. Access to Pre-Exposure Prophylaxis or PrEP and Post Exposure Prophylaxis or PEP, and antivirals for high-risk patients. When vaccination does not provide protection, there must be adequate access to appropriate therapies to prevent and treat infections. A critical claim, it can be achieved by accelerating the production and equitable distribution of antivirals and pre-exposure COVID-19 monoclonal antibodies
3. Using scientific rigour to best define who is at high risk for COVID-19. It cannot be based on a single blood value and instead should be informed by the increasing volume of scientific literature on COVID-19 outcomes in several different IC communities. This is especially true for all those with lymphoid malignancies including many lymphomas such as CLL/SLL (chronic lymphocytic leukaemia/small lymphocytic lymphoma), regardless of whether they are before, during or after treatment.
4. More research is needed about blood cancer and IC patients and existing and future antivirals.
5. Ensuring equitable access to best practices and treatments as well as affordable PPE and COVID-19 tests regardless of geographic, socio-economic, racial or ethnic considerations.
6. All those who might benefit should be offered additional vaccine doses. Booster vaccine doses should be offered especially to the elderly and immunocompromised based on studies demonstrating their protective benefits.
7. Involvement of the medical institutions in low and middle income countries in the clinical studies / trials of new anti-COVID-19 medications.
8. Provision of psychological and psycho-oncological services specifically to the immunocompromised who need to continue shielding and social distancing despite the relaxation of public rules. Offering the right protective measures complete with a comprehensive strategy to protect the patients from the multiple stressing factors of being immunocompromised, less protected than others, being in lockdown or otherwise shielding from the environment will lead to better physical and mental health outcomes.



- Vaccines must be made available globally, not only in high income countries. Reliable information about vaccines and treatments should be made available and more visible.

5. Implementation of said Recommendations and Concept of the ICBCC 2022 Campaign

In terms of concept, the 2022 campaign has three distinct objectives and addressees: policy makers, researchers and the public – each of whom can contribute in their own specific way to addressing the specific needs of IC patients, i.e. taking them into account in health policy decisions, clinical trial design and new research endeavours, and lending a voice to the most vulnerable. These stakeholders, including the general public, are addressed with targeted messages tailored to their field of responsibility and areas of influence.



As for content, the campaign essentially relies on 3 mediums: social media posts across two platforms (a dedicated [Twitter](#) account, and Facebook via the account of the [CLL Advocates Network](#)) including a Social Media Publishing Calendar, three different flyers, each directed at one of the three stakeholders, and two editable letter templates. The materials were created by [Patvocates](#), a think tank, consultancy and social enterprise in the area of patient advocacy and patient engagement, and with the help of a graphic design agency and translated into 14 languages (Arabic, Croatian, Czech, Estonian, French, Greek, Hebrew, Macedonian, Romanian, Russian, Serbian, Spanish and Swahili). All materials can be found on [the ICBCC website](#).

The online campaign was formally launched post [EHA](#) in the week of **20-24 June**. Coalition members and supporters were encouraged to help spread the message and promote the materials on the local level, across their Social Media accounts and other online channels.



6. Attendance at Events & Congresses

A. Attendance at the EHA 2022 Hybrid Congress

The ICBCC was also represented and promoted at the EHA 2022 Hybrid Congress in Vienna, Austria. With 10,000 participants on site and another 4,000 joining the congress virtually this year, the EHA is the leading meeting place for haematologists in Europe and beyond, and the European Haematology Association is a key endorser of the ICBCC Patient Impact Statement.

The ICBCC was represented at the 2022 'Patient Advocacy Hub' that – as in previous years – was part of the 'Collaboration Plaza' in the EHA Exhibition Hall. Points of contact on site were Pierre Aumont (Vice-Chair of the CLL Advocates Network as host of the ICBCC campaign) and Nicole Schröter (Project Manager CLL Advocates Network).



At the congress, printed ICBCC flyers and printouts of the coalition's patient impact statement to the congress were distributed widely and were freely available on the convention floor.

One of the campaign sponsors (see [9. Sponsors](#)) devised a fund-raising event to the ICBCC campaign through CLL Advocates Network as the coalition's formal host: signatures were collected during the 5 days of the congress and 5 Euros were donated by the sponsor post-event per signature; a total of 215 signatures were gathered, for a total donation of 1,075 euros, which will be used solely to support the ICBCC campaign.



B. ICBCC Representation at the 13th International Workshop of the German CLL Study Group (September 9-10)

The International COVID-19 Blood Cancer Coalition (ICBCC) was represented and promoted at the [13th International Workshop of the German CLL Study Group](#) which took place in Cologne, Germany as a hybrid event from September 9-10. Similarly to EHA 2022, one of the six ICBCC sponsors devised a fund-raising event to the ICBCC campaign through CLL Advocates Network (CLLAN) as the coalition's formal host. Signatures from congress visitors were collected, and 10 Euros were donated by the sponsor post-event per collected signature. The donated funds are utilised solely and exclusively to support the ICBCC campaign. Besides, printed materials were disseminated throughout the conference.

C. ICBCC Presentation at ESMO 2022 (September 9-13)

The ICBCC project was accepted as one of the topics presented within the Patient Advocacy session "Join us, learn, and share: Best practices across Europe" (session chairs: Agata Polinska, PL; Petra Adamkova, CZ) at this year's congress of the [European Society for Medical Oncology \(ESMO\)](#) held in Paris, France, September 9-13, 2022. The project was presented by Jana Pelouchová, president of the Leukemia Patient Advocates Foundation, Steering Committee Member of the CLL Advocates Network acting as secretariat for the ICBCC on behalf of the coalition, and ESMO PAWG Member. What is more, materials were disseminated throughout the congress.



7. Twitter Performance Analysis & Statistics

A. #ICBCC Overall Twitter Hashtag Analysis (20-24th June 2022)



B. Top Tweets: Most Engagement

Blood Cancer UK

@bloodcancer... · Follo
w

Since #immunocompromised blood cancer patients are not protected by vaccines against COVID-19, they rely on the help of the community.

#ICBCC calls on your help to protect those who cannot protect themselves by continued vaccination and wearing of masks. #considerthecompromised

10:44 AM · Jun 21, 2022

53 See latest COVID-19 info

[Read 1 reply](#)

European Hematology ...

@EHA_Hematol... · Follo
w

2-3% of the global population are #immunocompromised. They, including blood cancer patients, are at greater COVID-19 infection risk & cannot rely on vaccination alone. #ICBCC calls on stakeholders to improve research, access, & support for IC patients. #considerthecompromised

1:01 PM · Jun 23, 2022

13 See latest COVID-19 info

[Explore what's happening on Twit...](#)

European Hematolog...

@EHA_Hematol... · Follo
w

With COVID-19 restrictions lifting, we must consider the needs of immunocompromised blood cancer patients who are at greater risk of infection and severe disease. #ICBCC calls on stakeholders to increase care access for patients and #considerthecompromised.

3:00 PM · Jun 21, 2022

16 See latest COVID-19 info

[Explore what's happening on Twit...](#)



C. Top Tweets: Most Likes

Blood Cancer UK @bloodcancer_uk · Follow

Since #immunocompromised blood cancer patients are not protected by vaccines against COVID-19, they rely on the help of the community.

#ICBCC calls on your help to protect those who cannot protect themselves by continued vaccination and wearing of masks. #considerthe compromised



10:44 AM · Jun 21, 2022

53 See latest COVID-19 info

Read 1 reply

ICBCC @icbcc_info · Follow

This is why the #ICBCC campaign is so important. Patients cannot live their lives until Governments make decisions and #considerthe compromised Show your support by RT #BehindTheMask Please share the @icbcc_info statement @CLLAdvocates @evusheld4theuk



Angela Rebel With M

We are trying to get attention for the immunosuppressed who are being denied treatment to prevent us dying from Covid. We want to get #BehindTheMask trending, so can I ask my followers to Tweet & RT, using the hashtag. You can find out more here: getevusheld.uk Thank you



7:38 AM · Jun 27, 2022

35 See latest COVID-19 info

Read 4 replies

Michael Rynne @MichaelRynne1 · Follow

More than 1 in 4 blood cancer patients do not produce COVID-19 antibodies & carry a high risk of severe disease course and death. #ICBCC calls for a change in health policy & access to life-saving treatments to protect those at risk! #ForUsAll #considerthe compromised



8:51 AM · Jun 20, 2022

Read the full conversation on Twitter

35 See latest COVID-19 info

Read 2 replies

CLL Society Inc. @CLLSociety · Follow

Wearing a mask is no longer mandatory in many countries which puts #immunocompromised blood cancer patients, who often cannot produce antibodies, at extreme risk. Please help protect these people by wearing a mask in public spaces. #considerthe compromised #ICBCC



4:13 PM · Jun 24, 2022

24 See latest COVID-19 info

Jan Geissler @jangeissler · Follow

Everyone can get a vaccine, but not every blood cancer patient can be protected because their immune system can't do the job. #considerthe compromised: #ICBCC calls on researchers & policy makers to prioritize access to protective antibody treatments. See icbcc.info



8:00 PM · Jun 20, 2022 from Munich, Germany

23 See latest COVID-19 info



D. Top Tweets: Most Retweets

Blood Cancer UK @bloodcancer_uk · Follow

Since #immunocompromised blood cancer patients are not protected by vaccines against COVID-19, they rely on the help of the community.

#ICBCC calls on your help to protect those who cannot protect themselves by continued vaccination and wearing of masks. #considerthecompromised



10:44 AM · Jun 21, 2022

53 See latest COVID-19 info

Read 1 reply

ICBCC @icbcc_info · Follow

This is why the #ICBCC campaign is so important. Patients cannot live their lives until Governments make decisions and #considerthecompromised

Show your support by RT #BehindTheMask

Please share the @icbcc_info statement @CLLAdvocates @evusheld4theuk



Angela Rebel With M

We are trying to get attention for the immunosuppressed who are being denied treatment to prevent us dying from Covid. We want to get #BehindTheMask trending, so can I ask my followers to Tweet & RT, using the hashtag. You can find out more here: getevusheld.uk Thank you



7:38 AM · Jun 27, 2022

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Read 4 replies

Michael Rynne @MichaelRynne1 · Follow

More than 1 in 4 blood cancer patients do not produce COVID-19 antibodies & carry a high risk of severe disease course and death. #ICBCC calls for a change in health policy & access to life-saving treatments to protect those at risk! #ForUsAll #considerthecompromised



8:51 AM · Jun 20, 2022

Read the full conversation on Twitter

35 See latest COVID-19 info

Read 2 replies

LLSCanada @LLSCanada · Follow

We are part of a multi-stakeholder alliance - the International COVID-19 Blood Cancer Coalition #ICBCC - to address the impact of COVID-19 on #immunocompromised blood cancer patients and to develop solutions to mitigate the risks for those affected. #considerthecompromised



3:18 PM · Jun 20, 2022

21 See latest COVID-19 info

Michael Rynne @MichaelRynne1 · Follow

Remember when we had no vaccines and all at risk from covid. Well now we have forgotten our #immunocompromised who don't have protection from vaccination and are calling for access to protective treatment #Evusheld

Support the #ICBCC campaign. #considerthecompromised

CLL Ireland @CllIrela...
#ICBCC campaign wants patients to be prioritised for covid therapeutics before and after infection. #immunocompromised



8. Outlook: ICBCC Survey and Follow-up

Following up on the campaign launched across the communities of CLL patients and beyond, the ICBCC secretariat is currently running [a survey](#) for the participating organisations to explore the impact of the campaign. The survey contains questions that not only aim at evaluating the campaign and its materials, but also assessing the additional needs and requirements of the patient community and of the organisations that have been participating in the ICBCC campaign.

While final results are pending, initial feedback is positive and shows that with an average rating of 5.5 (on a scale from 1 to 7 with 1 = Not useful at all and 7 = Very useful) the campaign was useful to most (Question: *To what extent do you find these materials useful for your advocacy work for better access to COVID-19 pre- and post-exposure prophylaxis for people living with blood cancer?*). The question *“Do you think that the specific needs of people living with blood cancer and exposed to COVID-19 are considered by the healthcare system in your country?”* got an average rating of 4,79 on a scale from 1 to 7 with 1 = Not considered at all and 7 = Completely considered and respected). Survey answers however are in some cases inconsistent within themselves (one reply does not go with the reply given in a previous question). Overall, this still shows that there is still an unmet need and room for improvement in many countries. To the question *“Is pre-exposure prophylaxis (Evusheld™) available and accessible in your country?”* 42.86 % answered with “Yes” and 35.71 with “No”, and the other 21.43 with “Under certain conditions”. To the question *“Is post-exposure prophylaxis (Paxlovid™ or antivirals or antibody treatment) available and accessible in your country?”* 57.14 % responded with “Yes” and 14.29 with “No”, and the other 28.57 with “Under certain conditions”.

The survey is expected to generate more traction and attention in order to promote the general impact of the campaign. At the same time, suggestions from the respondents may guide us further in terms of future activities.



9. Sponsors of the ICBCC 2022 Campaign

ICBCC is grateful to the following supporters for their contributions and commitment:



10. Endorsers of the ICBCC 2022 campaign

A. Global Patient Organisations





Fernando Piotrowski, Executive Director
Asociación ALMA
(Argentina)



Chris Tanti, CEO
Leukaemia Foundation
(Australia)



Sharon Winton, CEO
Lymphoma Australia
(Australia)



Hyacinth Grimes, Vice President
Lymphoma and Leukemia
Foundation of Barbados
(Barbados)



Elke Stienissen, President
Lymphoma Association Flanders
(Belgium)



Reymond Vles, Chair
CLL Canada
(Canada)



Nadine Prévost, Senior Director
The Leukemia & Lymphoma
Society of Canada
(Canada)



Nury Esperanza Villalba Suárez, Executive Director
Fundación Esperanza Viva
(Colombia)



Silvia Diaz, President
AGALEMO
(Costa Rica)



Dražen Vincek, President
Hrvatska Udruga Leukemija i
Limfomi, HULL



Jana Pelouchova, President
Diagnóza Leukemie
(Czech Republic)



Rita O. Christensen, President
Patient Advocacy Group for





Lidija Pecova, President
HEMA
(Macedonia)



Mayra Galindo, Director
Mexican Association of the Fight
Against Cancer - AMLCC
(Mexico)



Bahija Gouimi, President
AMAL
(Morocco)



**Krishna Prasad Upadhyaya, Vice
Chairman**
Blood Cancer Society Nepal
(Nepal)



**Marianne van
Maarschalkerweerd, Expert
Patient Advocate**
Hematon
(The Netherlands)



**Emma Barker, Head of Support
Services & Operations**
Leukaemia & Blood Cancer New
Zealand
(New Zealand)



Dr Gillian Corbett, Trustee
CLL Advocates New Zealand,
CLLANZ
(New Zealand)



Oksana Chirun, President
Inter-regional public organization
for patients with hematological
diseases «Most Miloserdiya»
 («Mercy Bridge»)
(Russia)



Maja Kocic, President
Lymphoma Patient Association
LYPA / LIPA
(Serbia)



**Kristina Modic
Executive Director**
Slovenian Lymphoma and
Leukemia Patient Association, L&L
(Slovenia)



**Elena Palma, International
Representative**
AELCLES (Spanish Network for
Leukemia and Blood Disorder)
(Spain)



Lise-Iott Eriksson, President
Blödcancerförbundet / The
Swedish Blood Cancer Association
(Sweden)





Pierre Aumont, Trustee
Ensemble Leucémie Lymphomes
Espoir - ELLyE
(France)



Rainer Göbel, Chairman
Deutsche Leukämie- und
Lymphom-Hilfe, DLH
(Germany)



Jan Geissler, Founder
Leukaemie-Online.de
(Germany)



Jan Geissler, Chair
LeukaNET
(Germany)



Kimon Ourountzoglou
Hellenic Group of Patients with CLL
(Greece)



Vandana Gupta, Founder
V Care Foundation
(India)



Michael Rynne, Co-founder
CLL Ireland
(Ireland)



**Rachel Morrogh, Director of
Advocacy & External Affairs**
Irish Cancer Society
(Ireland)



Giora Sharf, Director
Flute of Light - Home of blood
cancer patients in Israel
(Israel)





Dr Jeroen Goede, President
SFK- Stiftung zur Förderung der
Knochenmarktransplantation
(Switzerland)



Rosmarie Pfau, President
Lymphome.ch Patientennetz
Schweiz
(Switzerland)



Gerard Masalago, Chairman
Blood Cancer Foundation
Tanzania
(Tanzania)



**Zack Pemberton-Whiteley, Chief
Executive Officer**
Leukaemia Care
(UK)



**Dallas Pounds, Director of
Services**
Lymphoma Action
(UK)



Marc Auckland, Chair
CLL Support
(UK)



**Helen Rowntree, Director of
Research, Services &
Engagement**
Blood Cancer UK
(UK)



Tom Mallon, Coordinator
Leukaemia & Lymphoma NI
(UK)



**Sophie Wintrich, Chief
Executive/Patient Liaison**
MDS UK Patient Support Group
(UK)



Dr Adrian Warnock, Founder
Blood Cancer Uncensored
(UK / USA / Canada)



Ivan Zelenskyi, Director
Charity Fund of patients "Drop of
Blood"
(Ukraine)



**Gwen Nichols, MD, Chief
Medical Officer**
The Leukemia & Lymphoma
Society
(USA)



Now a part of Remedy Health Media

Esther Schorr, Co-Founder
Patient Power
(USA)



B. Clinical community / Medical Societies



Elizabeth Macintyre, President
European Hematology Association,
EHA
(Europe)



Prof Paolo Ghia, President
European Research Initiative on
CLL, ERIC
(Europe)



Prof Peter Hillmen, Chairperson
International Workshop on Chronic
Lymphocytic Leukemia (iwCLL)
(Global)



Dr Yervand Hakobyan, President
AHA - Armenian Hematology
Association
(Armenia)



**Vanessa O'Shaughnessy,
Director Communications**
Peter MacCallum Cancer Centre
(Australia)

Dr Versha Banerji, Physician
(Canada)



**Prof Alain Delmer & Prof Pierre
Feugier**
CLL Scientific Board
French Innovative Leukemia
Organization
(France)

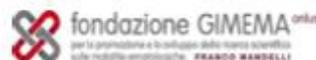


**Dr Kostas Stamatopoulos,
Director**
Institute of Applied Biosciences
CERTH - Center for Research and
Technology Hellas
(Greece)

Dr Alina Gerrie, Hematologist
British Columbia
(Canada)



Dr Tamar Tadmor, Physician
The Israeli CLL Study Group
(Israel)



Dr Marco Vignetti, President
GIMEMA
(Italy)



Dr Vasile Musteata, Physician
Society of hematologists and
transfusiologists
State University of Medicine and
Pharmacy "N. Testemitanu",
Institute of Oncology
(Moldava)



Dr Renata Walewska, Chair
UK CLL Forum
(UK)



UNIVERSITY OF
BIRMINGHAM

Prof Paul Moss, Physician
Chief Investigator of the CLL-
Vaccine Response Study,
Birmingham



Prof Adele Fielding, President
British Society for Haematology
(UK)





**Anne Crook, Counsellor /
Psychotherapist, Psycho-
oncology
(UK)**

**Dr Dominic Culligan, Chairman
UK MDS FORUM
(UK)**



**Nicole Lamanna, MD
Director CLL Program
Hematologic Malignancies Section
Herbert Irving Comprehensive
Cancer Center
New York-Presbyterian/Columbia
University Medical Center
(USA)**

