

THE ROCKEFELLER UNIVERSITY

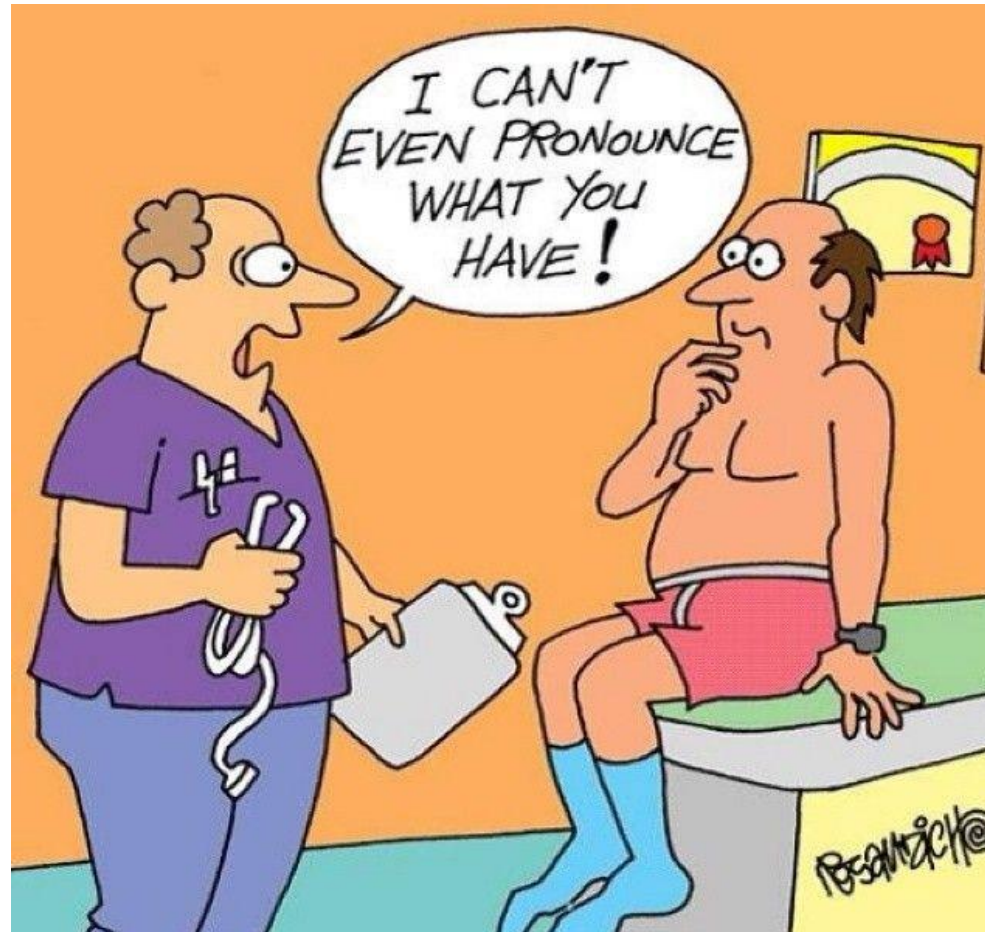


Shedding light on hidradenitis suppurativa (HS)

May 21, 2018

Carson Family Auditorium

Welcome!





Program

5:30–6:00 p.m.

Registration Opens, Light Snacks, and Networking

6:00 p.m.

Welcoming Remarks and Introductions

6:05 p.m.

What Causes HS?

Michelle Lowes, MB.BS, Ph.D.

*Associate Attending Physician, The Rockefeller University
Hidradenitis Suppurativa Foundation (HSF) Board Member*

6:20 p.m.

Treatment Options for HS

Afsaneh Alavi, M.D., M.S.

*Assistant Professor
Women's College Hospital, University of Toronto
Canadian Hidradenitis Suppurativa Foundation (CHSF)
Past President*

6:35 p.m.

Translational Approach to Chronic Skin Disease

James Krueger, M.D., Ph.D.

*D. Martin Carter Professor in Clinical Investigation
Director, Milstein Medical Research Program
Senior Attending Physician
Head, Laboratory of Investigative Dermatology
The Rockefeller University*

6:45 p.m.

HS Support Groups and Advocacy

Angela Parks-Miller, CCRP, CWCA

*Clinical Research Manager for Investigator Initiated Studies
Department of Dermatology, Henry Ford Hospital, Detroit, MI
Hope for HS
President and Founding Director
Hidradenitis Suppurativa Foundation (HSF)
National Director of Advocacy and Support*

7:00 p.m.

Living with HS

A panel of people living with HS share their experiences, including Sharon Hamilton and Athena Gierbolini

7:30 p.m.

Open Discussion with Panelists and Speakers

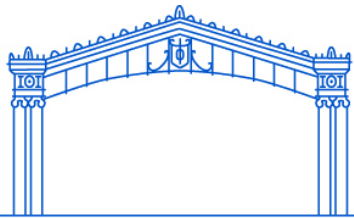
8:00 p.m.

Concluding Remarks, Followed by Networking

Reminders

- Q&A time at the end after all the speakers
- For webcast viewers, questions can be asked in the chat box
- We welcome general questions but we cannot answer your individual health questions
- Moving around

Thank you!



THE ROCKEFELLER UNIVERSITY HOSPITAL

CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE



Hidradenitis Suppurativa
Foundation (HSF)
hs-foundation.org



Hope for HS
hopeforhs.org



Canadian Hidradenitis
Suppurativa Foundation
(CHSF)
hsfoundation.ca/en/home



Symposium on Hidradenitis
Suppurativa Advances (SHSA)
October 12-14th, 2018
Toronto, Canada
hs-symposium.org



Dr. Loo



What causes hidradenitis suppurativa (HS)?

Dr. Michelle Lowes

Conflicts

- Incyte, Xbiotech- consultant for clinical trials
- AbbVie- consultant

How do we make a diagnosis of HS?

HS is a clinical diagnosis

Typical “lesions”:	Abscess (boils), nodules, tunnels
Typical places:	Armpit, under breasts, groin
Recurrent:	Over 6 months

What does HS look and feel like?

Pain

Drainage

Odor

Itch

Scars

Impact on QOL

Hurley Stage I



2/3

II



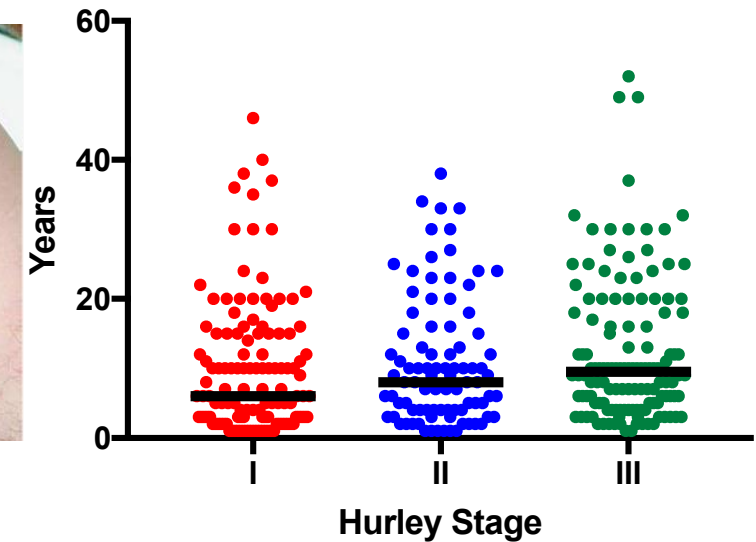
1/4

III



5%

Montefiore HSTC
Symptom Duration



Is HS rare?

~ 3 million people in North America!

HS is quite common

Originally classified as a rare disease

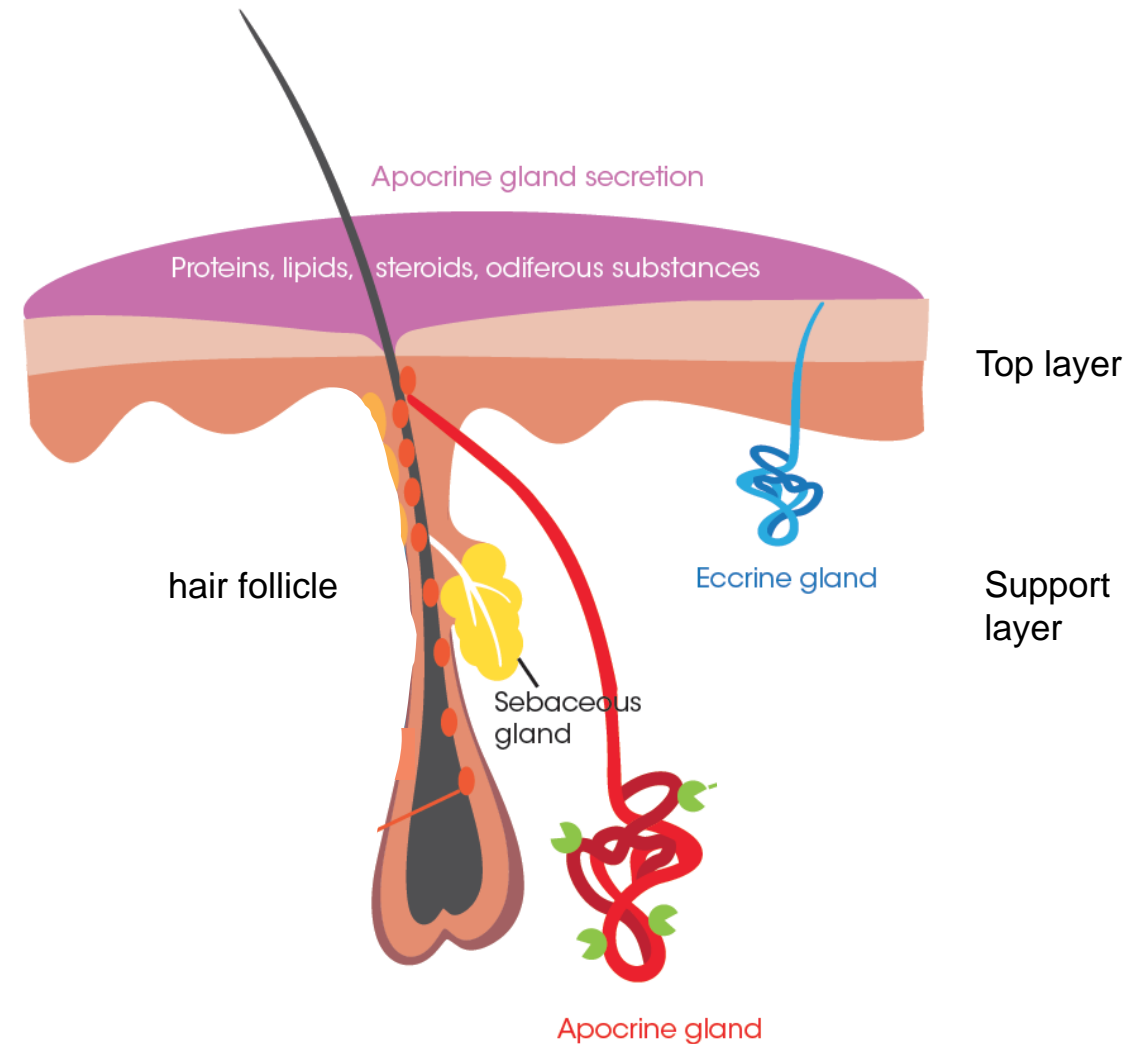
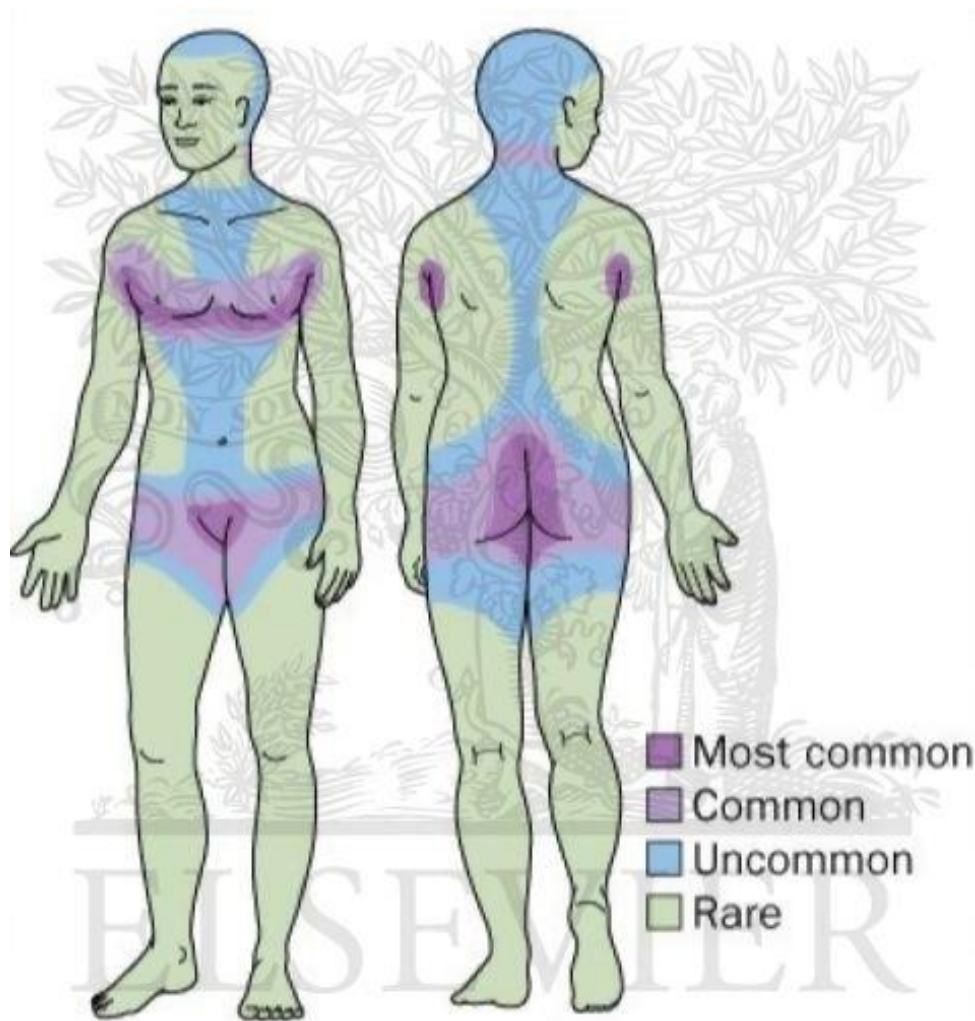
~1% of the population have HS worldwide



Women
African Americans

Average age of presentation is early 20's
Takes a decade to be diagnosed

Why does HS happen where it does?



How do individual HS “lesions” develop?

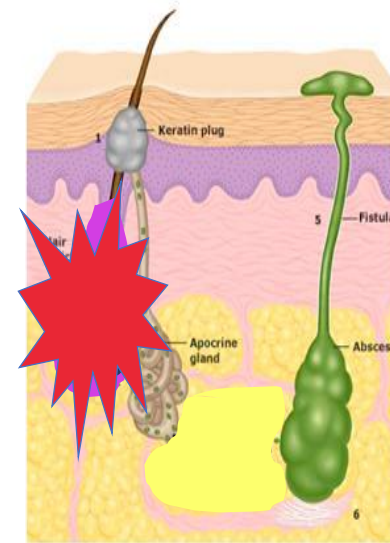
Blockage at top of the hair

Cyst develops, normal bacteria trapped in cyst

Cyst bursts outwards or sideways into skin

Bacteria and cells now in the lower part of the skin

Inflammation around hair and deeper skin

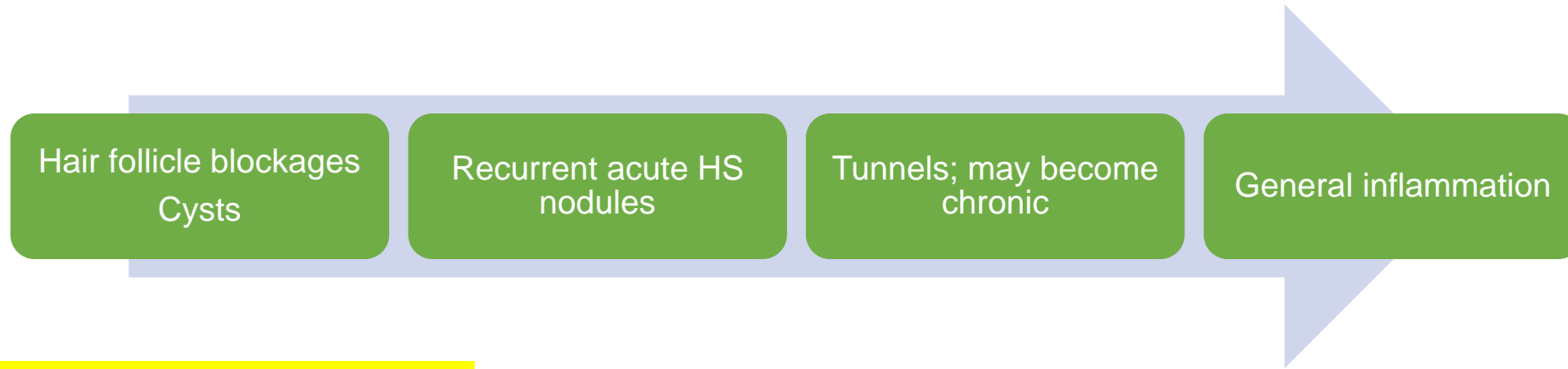


Top layer

Support layer

Sweat glands

What starts HS?



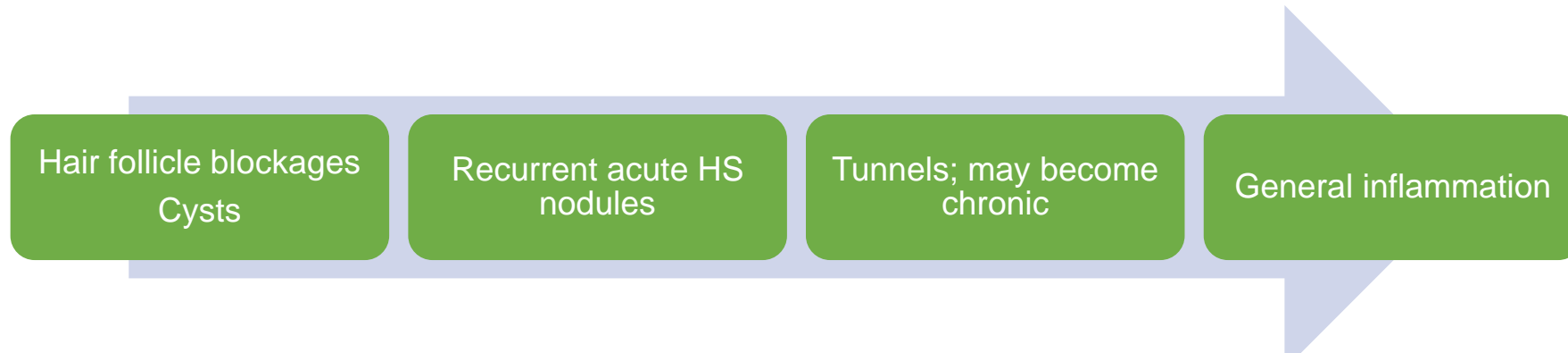
INITIATION:

- Structure of hair
- Apocrine sweat gland
- Environment: e.g. cigarette smoking
- Genetics

Is HS inherited?

- 1/3 of people have a positive family history
- A few families have changes in parts of the *gamma-secretase* genes
- This gene complex may have important roles in skin health & loss of function may cause inflammation

Why does inflammation persist in HS?



PROGRESSION:

Immune response is very strong
but ineffective: “auto-immune”

What is responsible? bacteria? other cells?

HS can be more than skin deep

HS Lesions

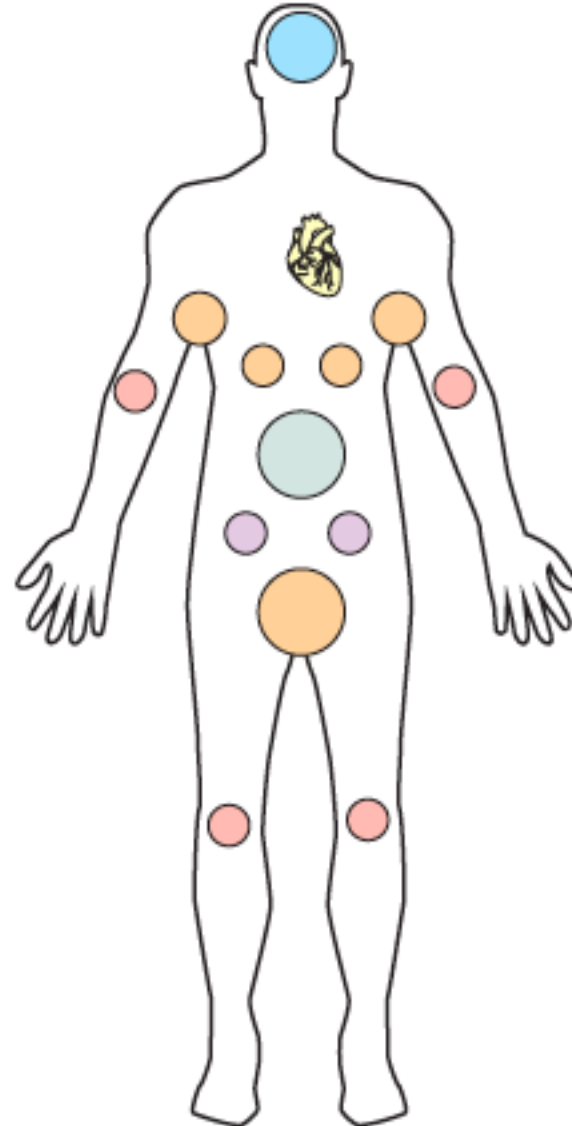
- Nodules and cysts
- Tunnels
- Pain
- Discharge
- Scarring

Psychological

- Impact on Quality of Life
- Anxiety
- Depression

Metabolic

- Obesity
- Metabolic Syndrome
- Heart health



Hoffman et al, SCMS, 2017

What HS is NOT:

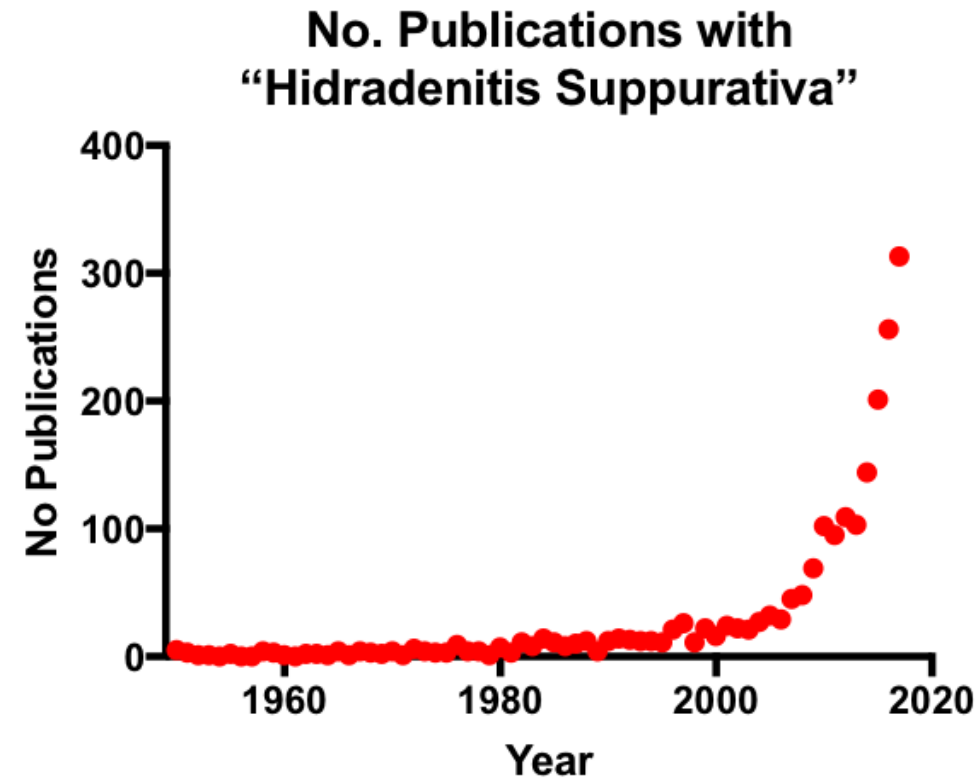
HS is **NOT** a primary infection

HS is **NOT** due to poor hygiene

HS is **NOT** contagious

HS is **NOT** due to something you did

HS – what's new in research?



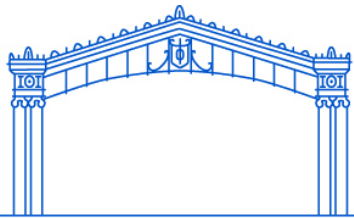
Publications are increasing

HSF Danby grants

New NIH/NIAMS funding opportunity for HS

HSFC-Pathway to a Cure-biobank

Thank you!



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Dr. Loo

Thank you!

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lowesm8@gmail.com



SHSA 2018

Symposium on Hidradenitis
Suppurativa Advances

ORGANIZED BY



Foundation, Inc.



SAVE THE DATES

October 12-14, 2018

Women's College Hospital, Toronto

Join us for the 3rd Annual Symposium on Hidradenitis Suppurativa Advances in 2018. This conference continues to grow and to bring together local and international HS physicians, surgeons and investigators to share their experiences, discuss innovations and treatments and increase awareness of this devastating disease.

Visit our website for up-to-date information.

www.hs-symposium.org



©Tourism Toronto

KEY DATES

Call for abstracts opens	April 15, 2018
Online registration opens	April 15, 2018
Deadline for abstract submissions	July 9, 2018
Abstract notification	August 9, 2018
Early registration deadline	August 31, 2018
SHSA 2018	October 12-14, 2018

www.hs-symposium.org

Treatment Options

Hidradenitis Suppurativa

Assistant Professor of Dermatology
Women College Hospital
Department of Medicine
University of Toronto



UNIVERSITY OF
TORONTO



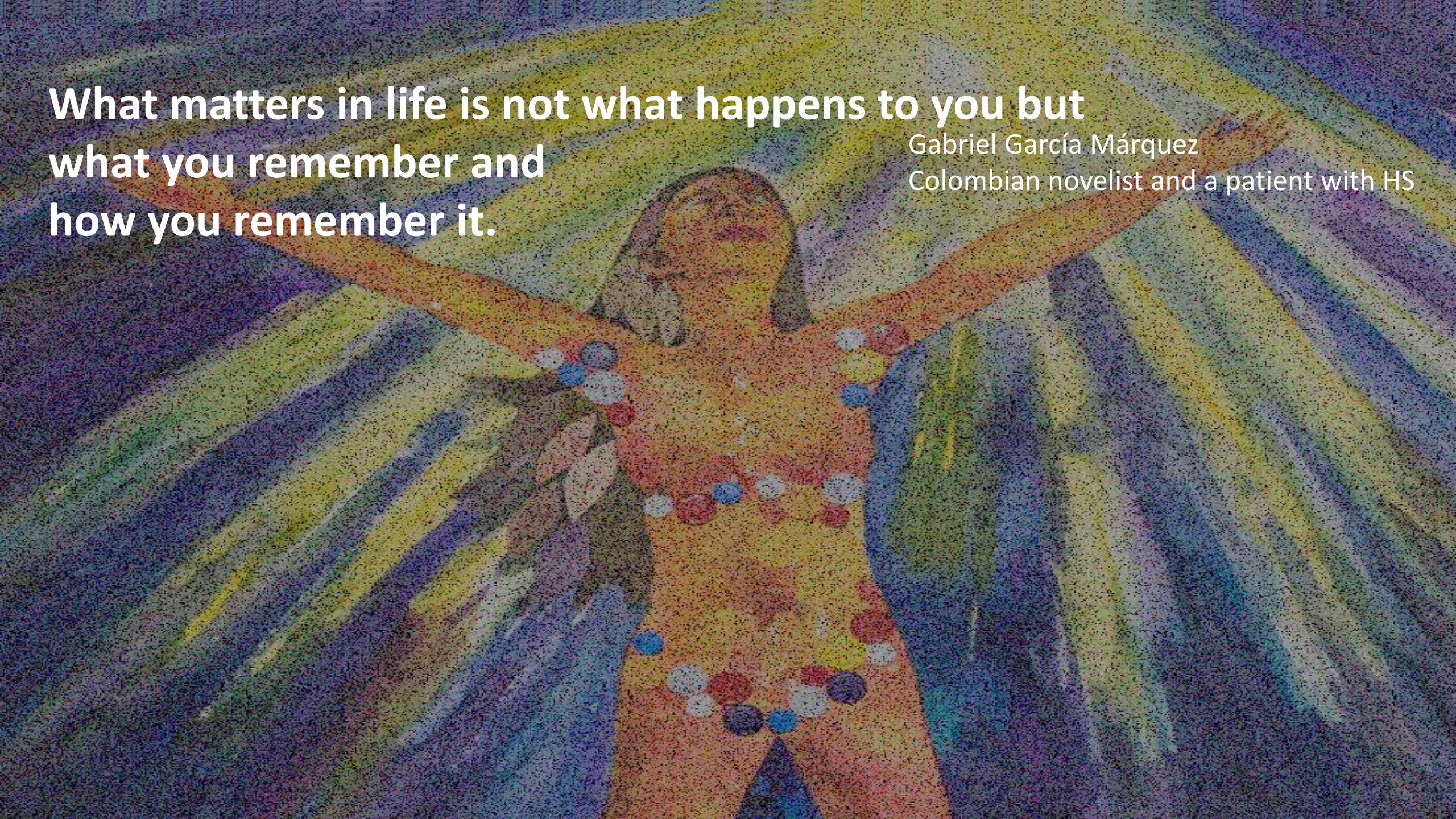
Outline

1. What are the main treatment options ?
2. How do antibiotics work?
3. How do immunosuppressive agents work?
4. What is the role of surgery?
5. What else I can do ?
6. How long is my treatment ?



**What matters in life is not what happens to you but
what you remember and
how you remember it.**

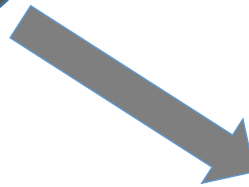
Gabriel García Márquez
Colombian novelist and a patient with HS



What are my options ?



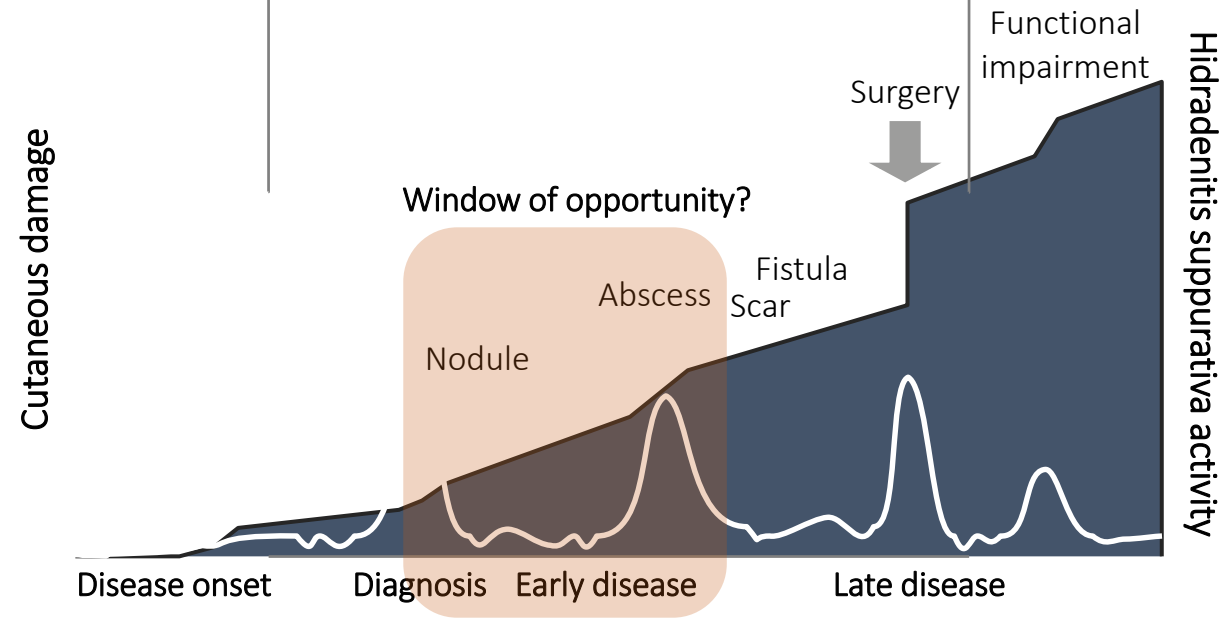
**Different
presentations**



**Personalized
approach**



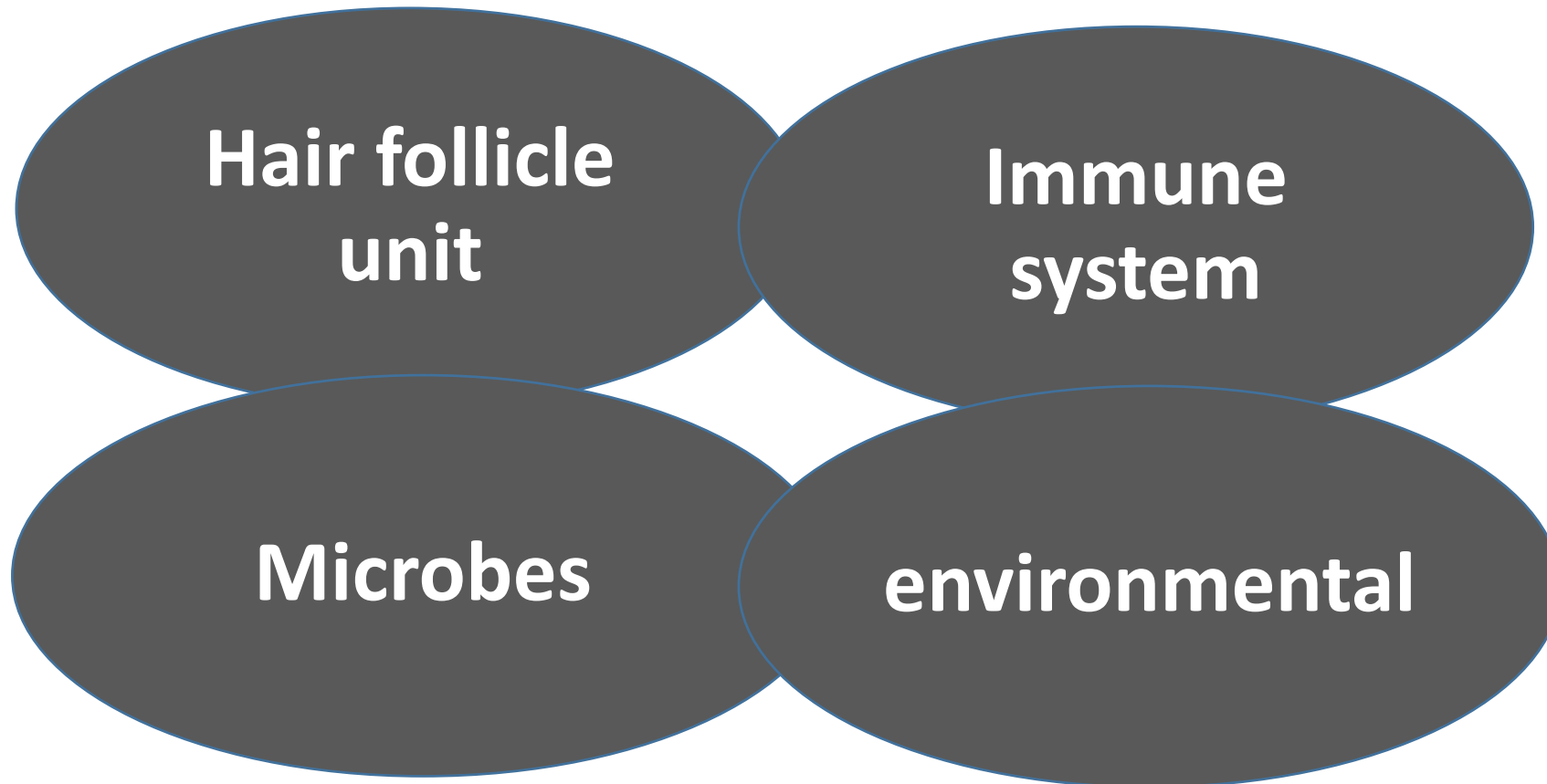
Timely treatment makes a difference!

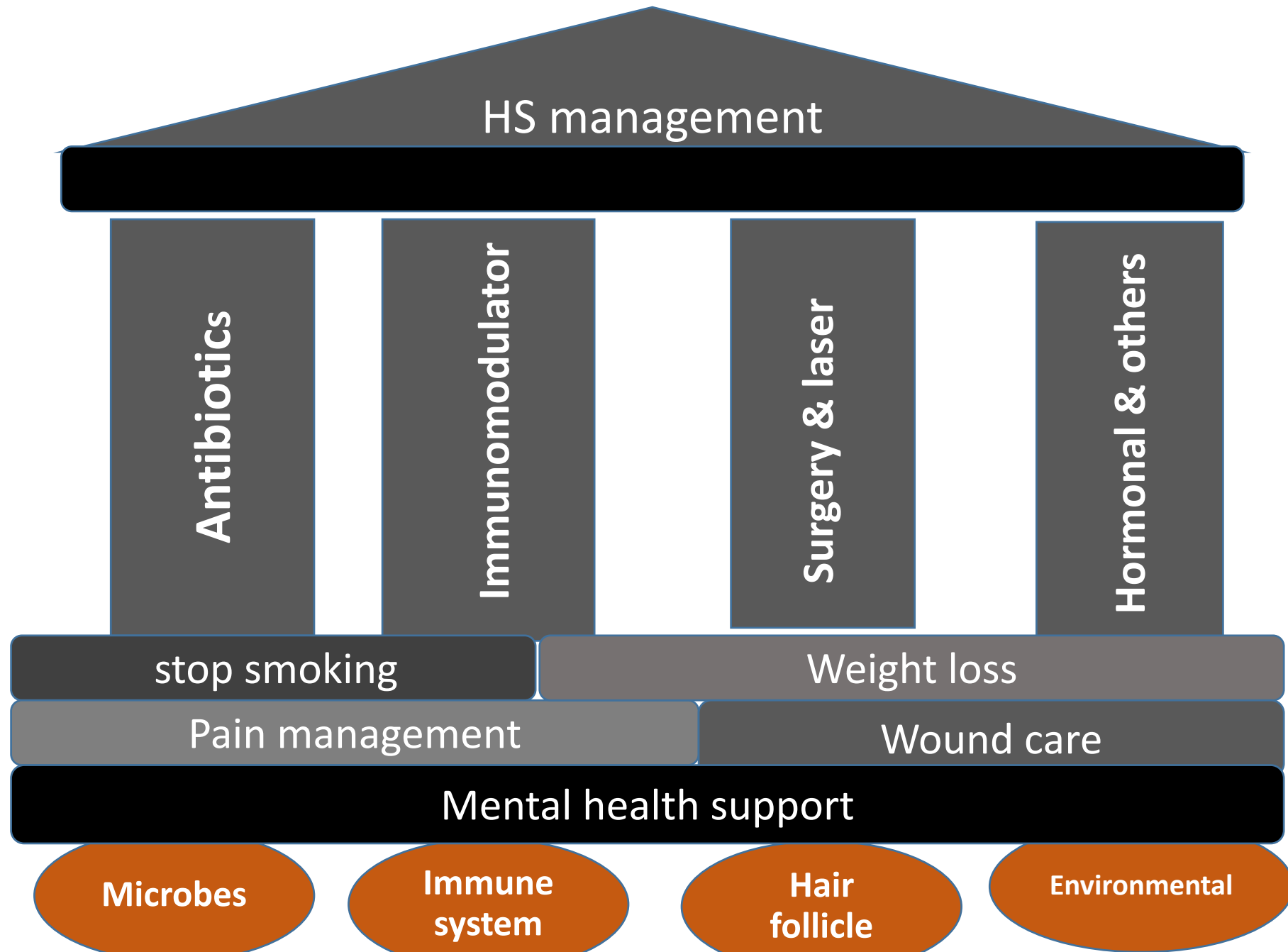


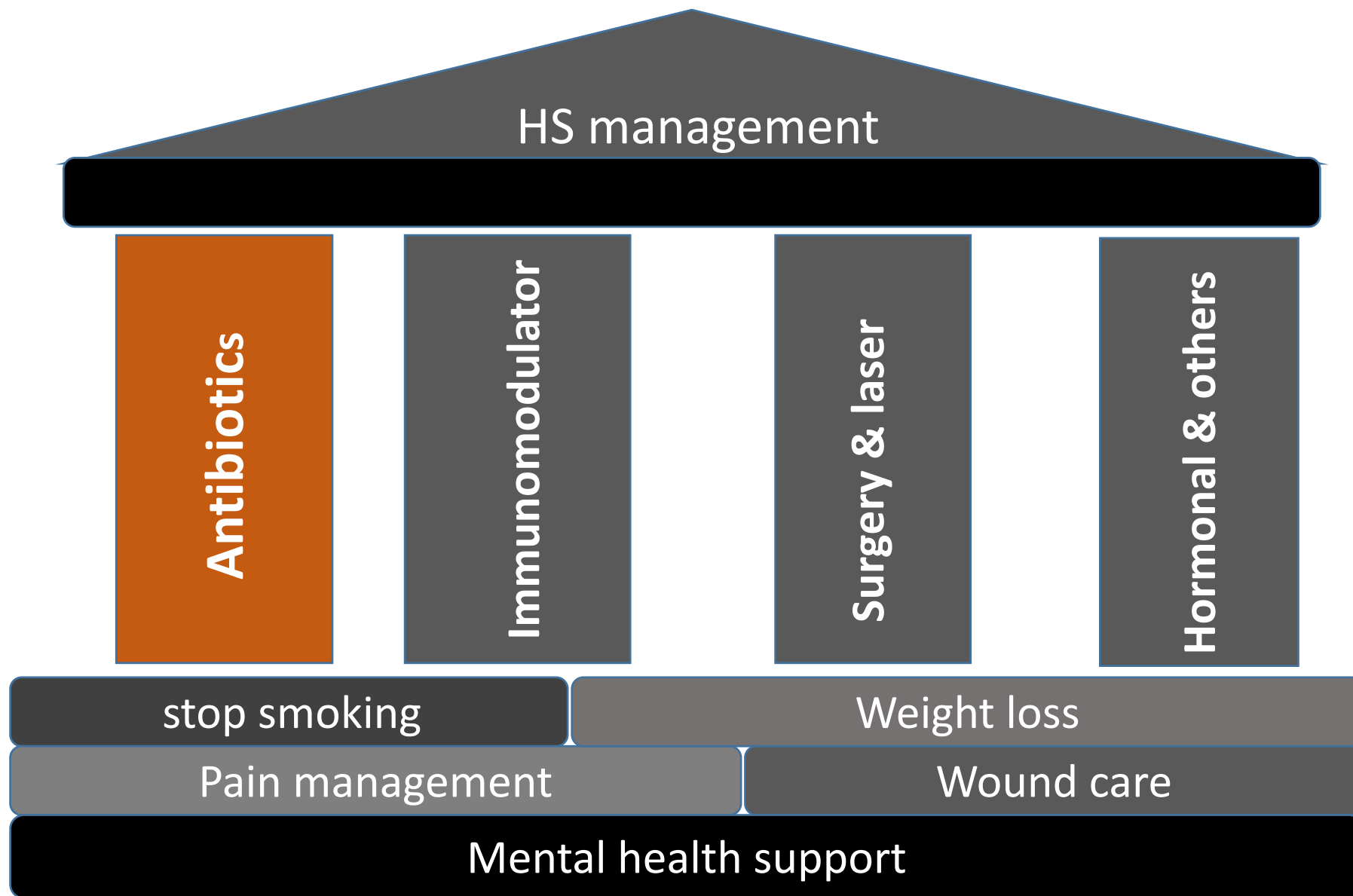
Courtesy of Eidon course

Martorell A, et al. Actas Dermosifiliogr. 2016;107 Suppl 2:32–42.

Pathogenesis

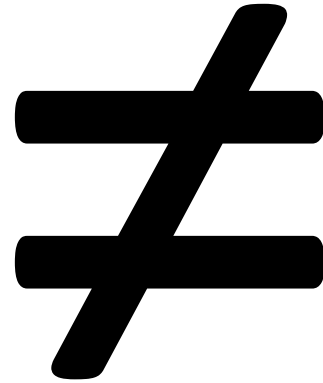






Why antibiotics?

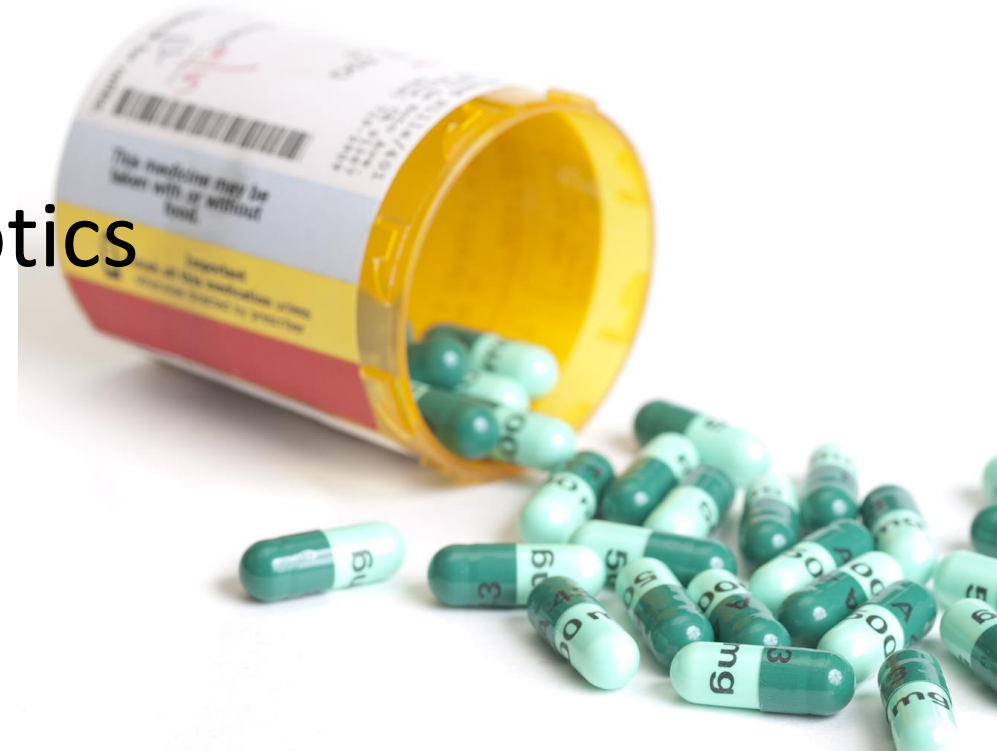
PUS

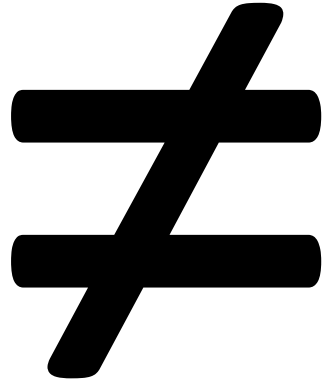


Infection

HS is not an infection but antibiotics play a role

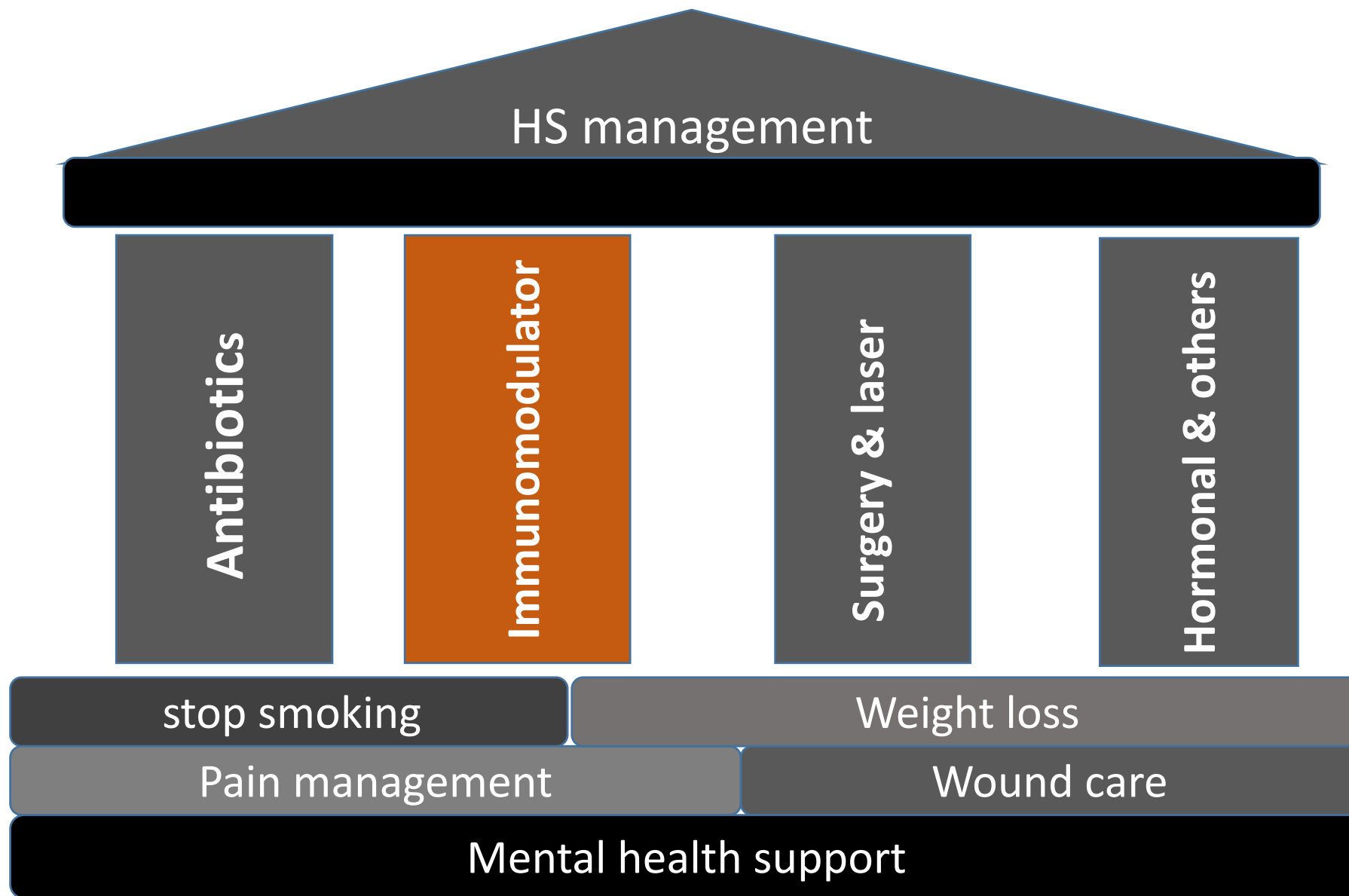
- High amount of commensal bacteria in deeper in skin
- Multiple organisms
- Richness of anaerobic bacteria
- Untargeted and well targeted antibiotics



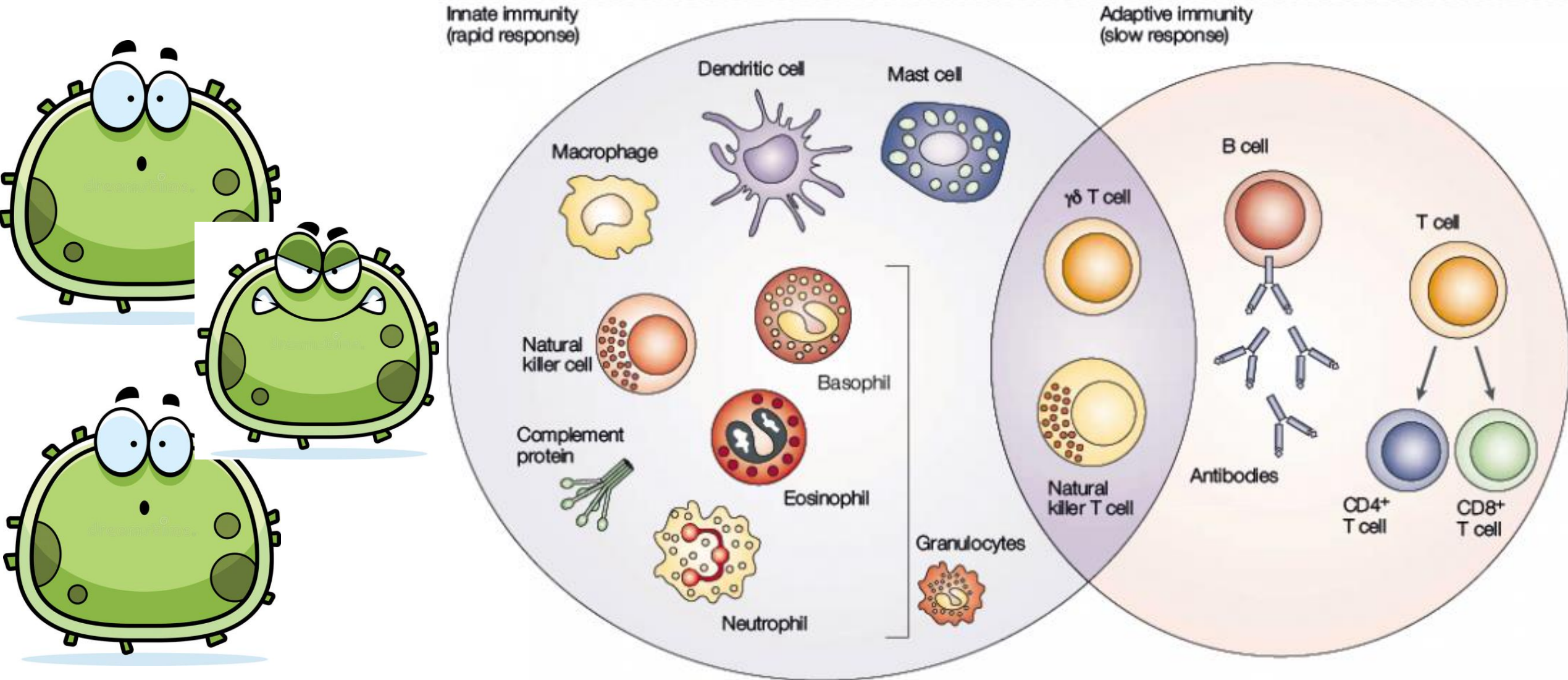


Transmission with close contact

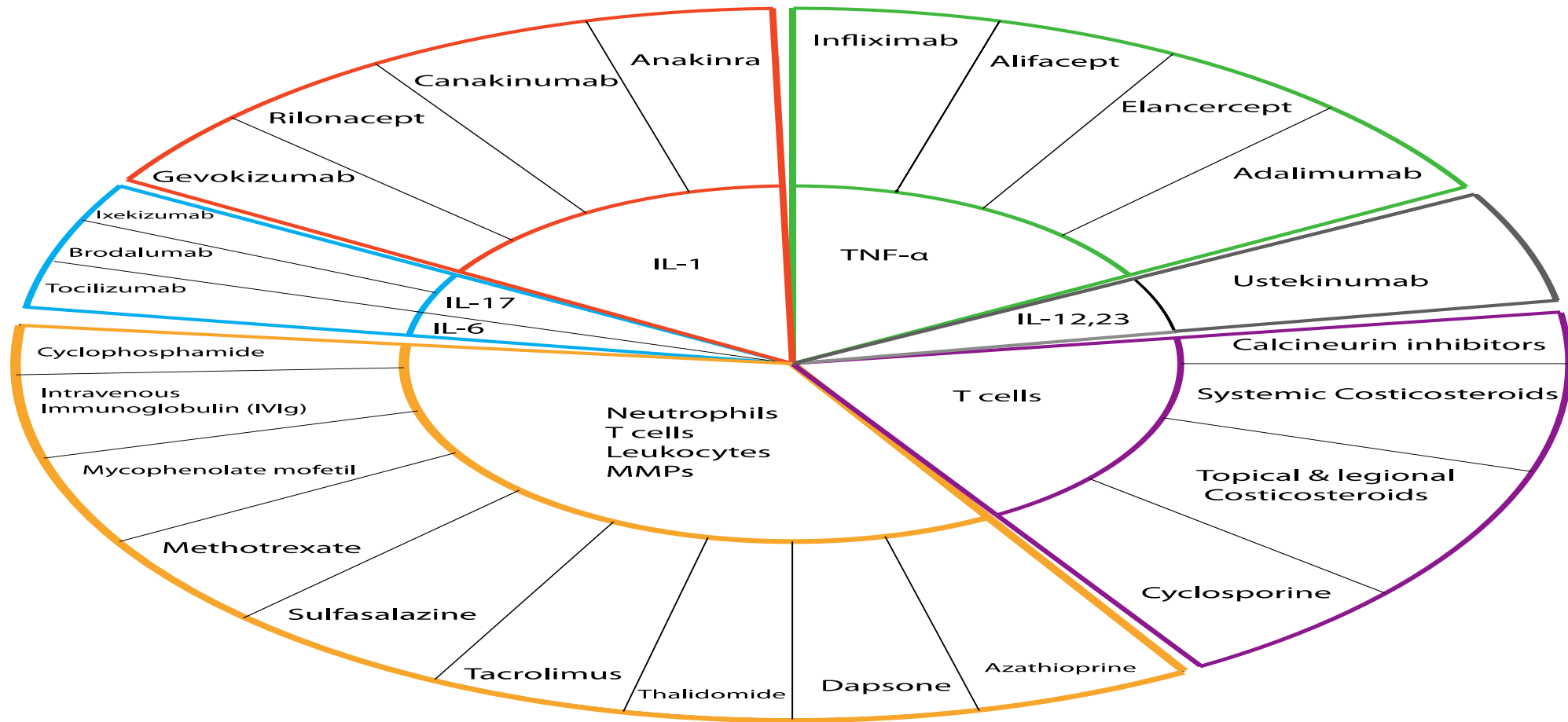
**household members, mother to child,
or intimate partners**

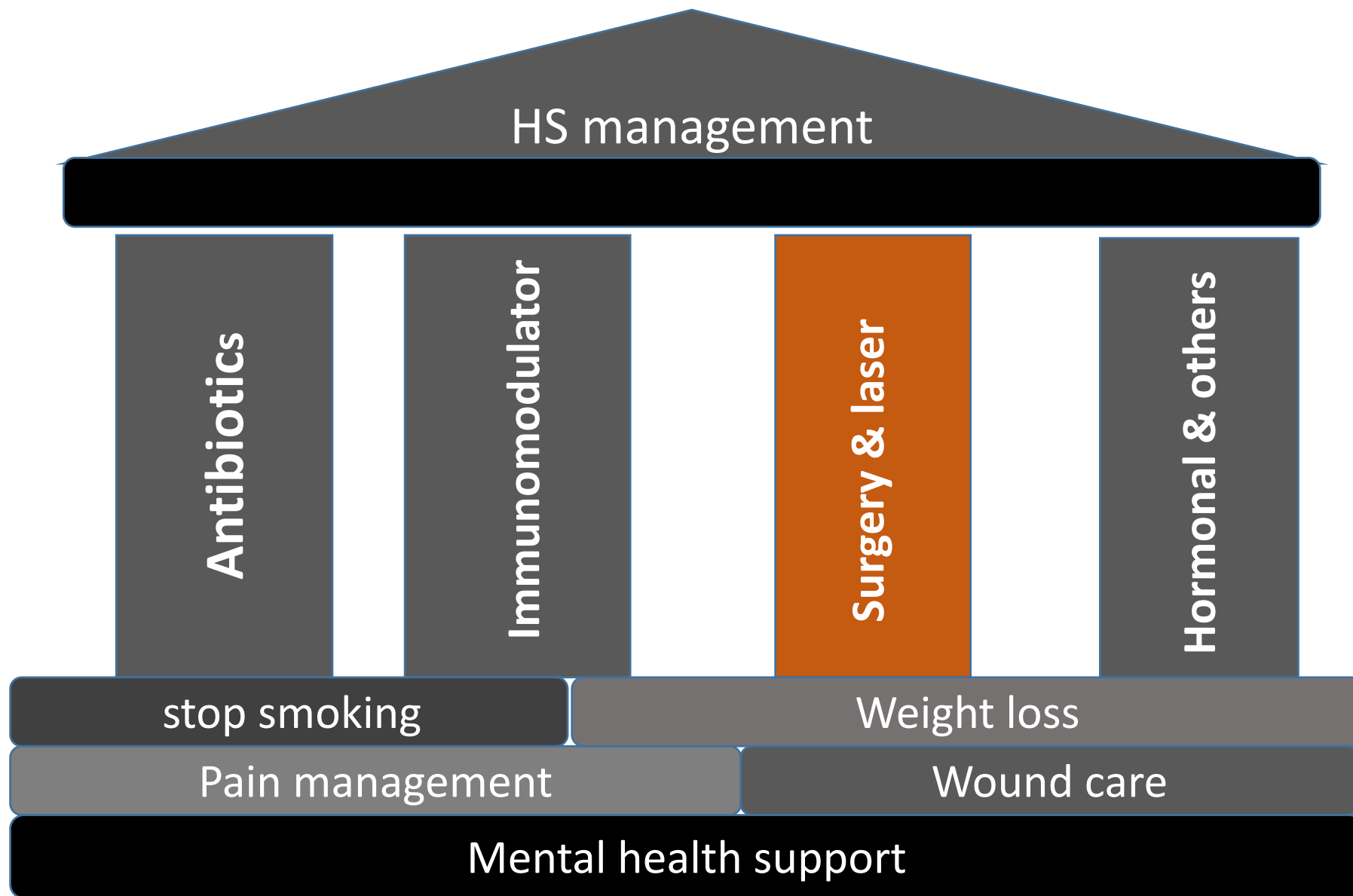


“keystone pathogens” that activate the host immune system



Why immunomodulators?



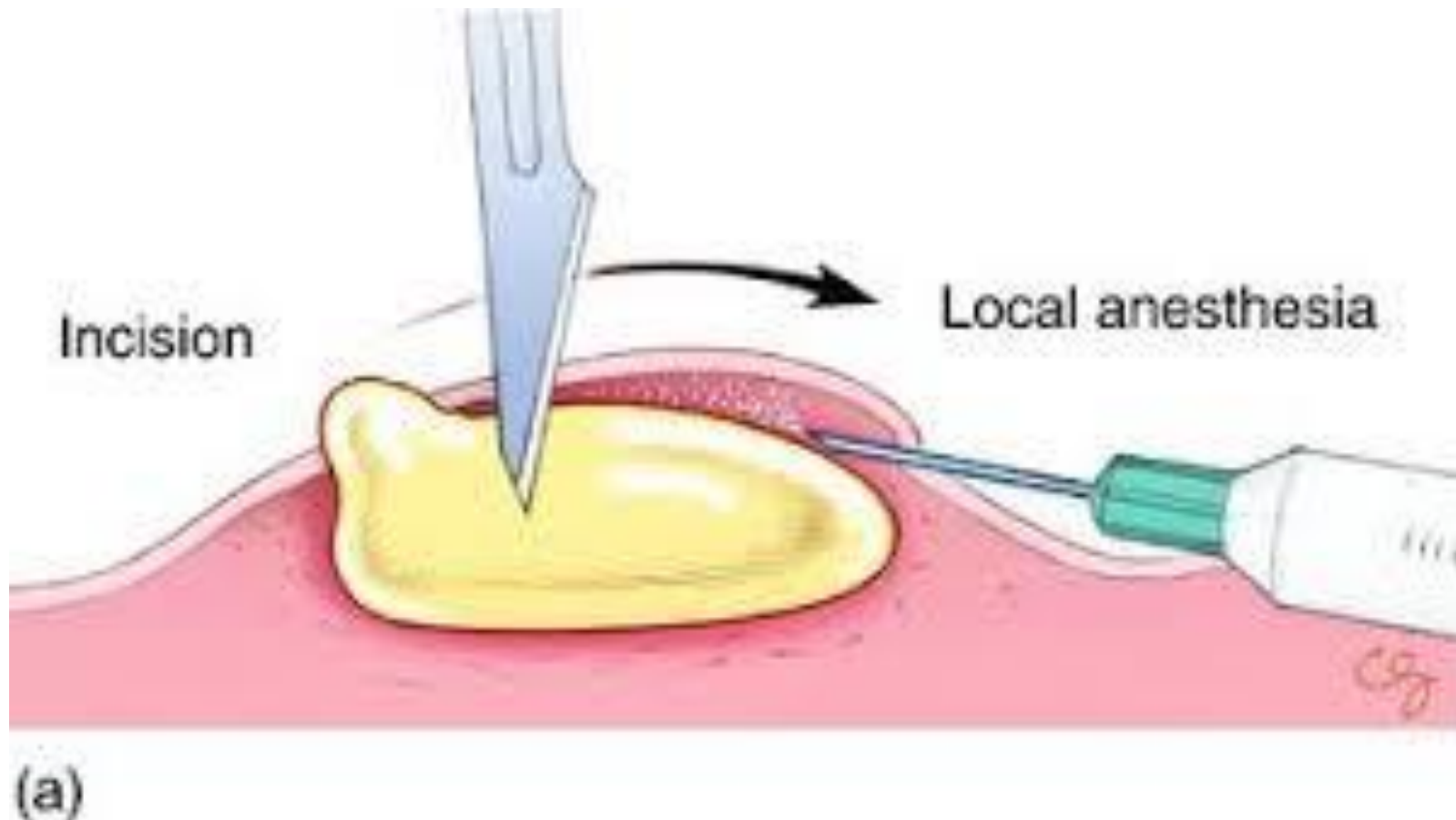


Surgical techniques

- Incision/Drainage
- Limited excision, de-roofing
- Wide surgical excision
- Laser- CO2 and hair removal



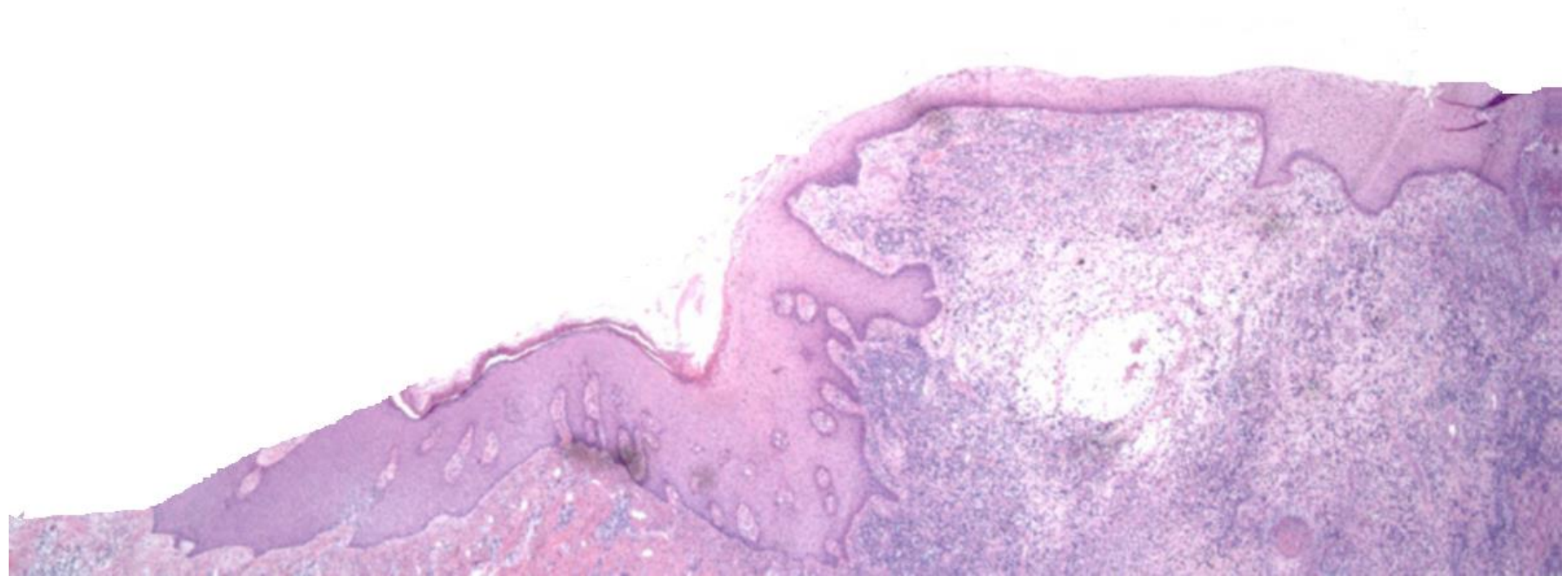
Incision and drainage : 100% recurrence



Deroofing

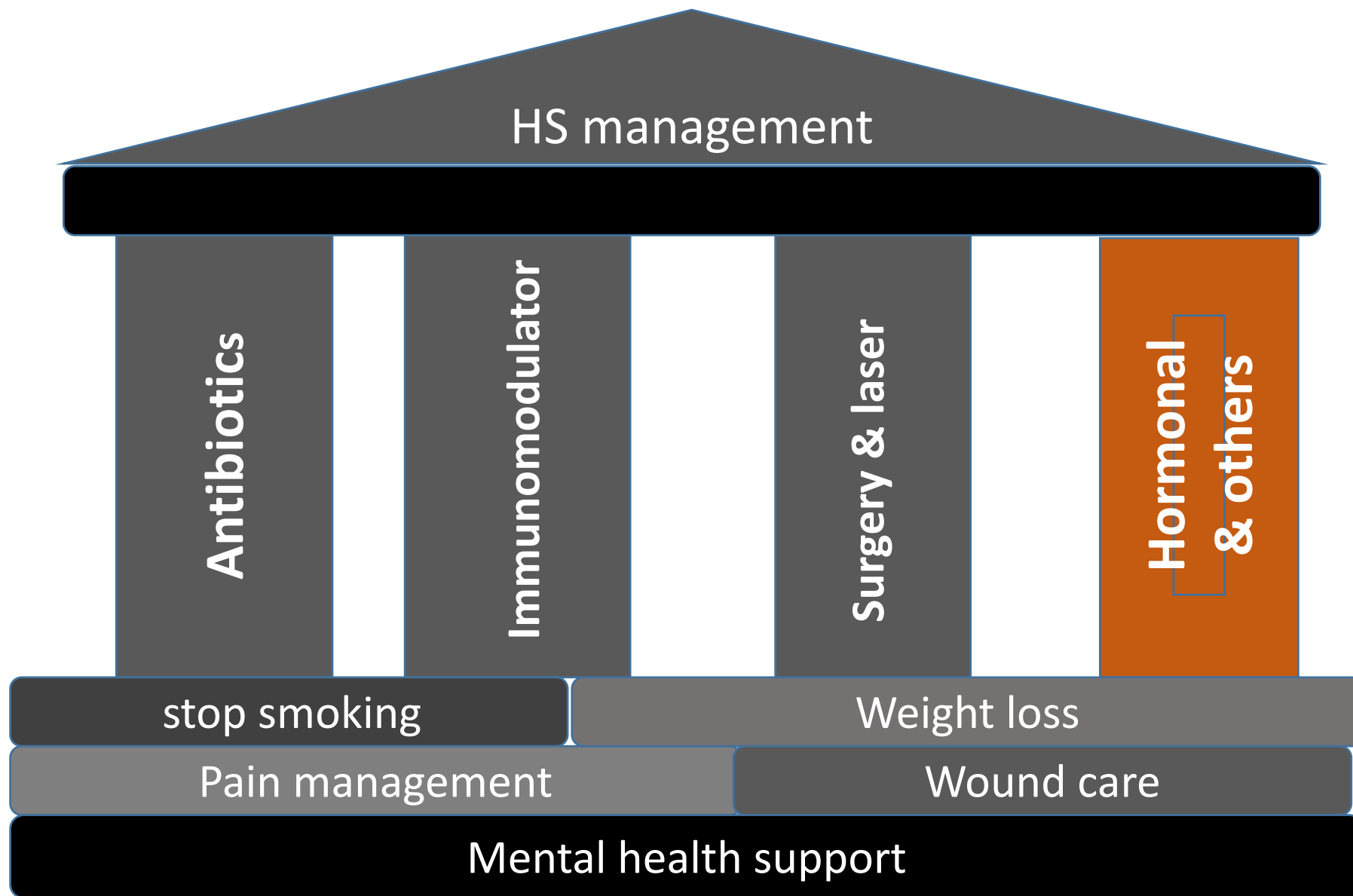


Courtesy of Dr Van der zee





Courtesy of Dr Van der zee



What else I can do ?

- Avoid triggers
- Weight loss
- Avoid smoking
- Antiandrogens
- Metformin
- Retinoids: comedonal
- Pain management: ask for help



Mental Health Support



You are not alone

Wound care

Absorptive, easy to apply, not costly, comfortable



Policy makers

genetics

**Reception-
Secretary**

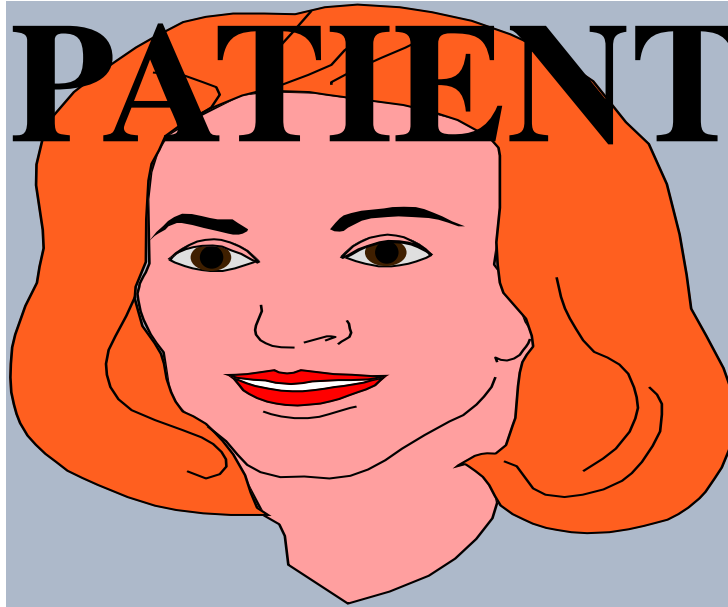
Dermatologist

Surgeons

Gastroenterologist

Radiologist

Clinic Nurses



Medical Internist

Endocrinologist

Dietitian

Pharmacist

**Social
Worker**

Psychiatrist

**Plastic
Surgeon**

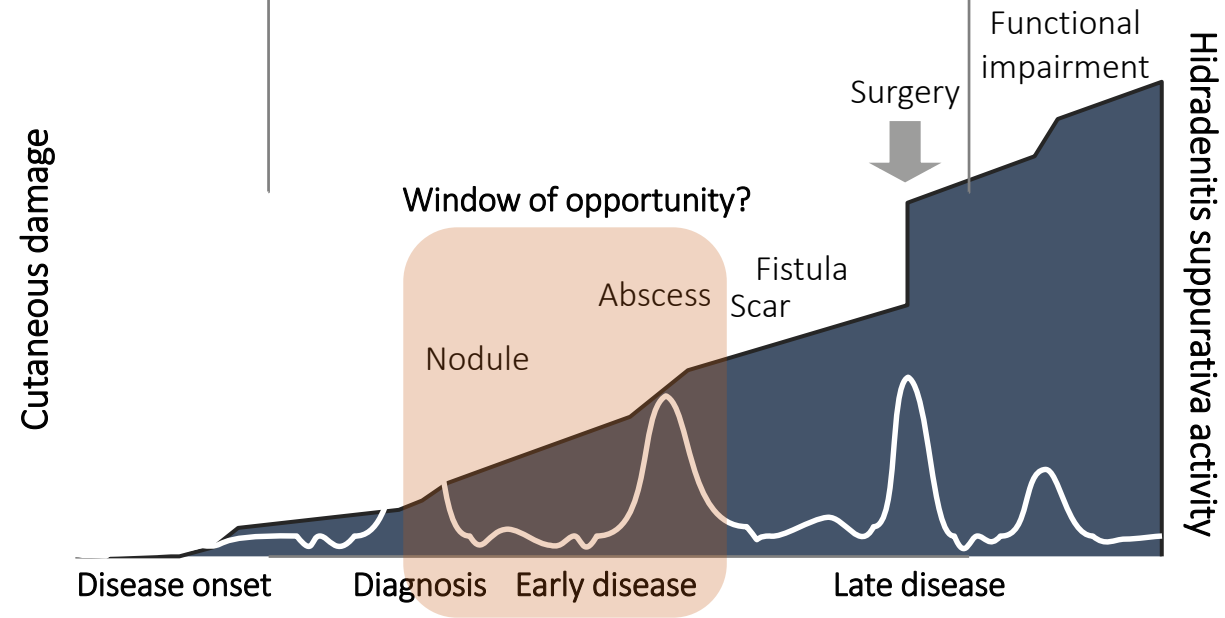
**Family
Doctor**

family

Physiotherapist

**Occupational
Therapist**

Timely treatment makes a difference!



Courtesy of Eidon course

Martorell A, et al. Actas Dermosifiliogr. 2016;107 Suppl 2:32–42.

Summary

1. What are my main treatment options ?
2. How do antibiotics work?
3. How immunosuppressive agents work?
4. What is the role of surgery?
5. What else I can do ?
6. How long is my treatment ?

The Translational Approach to Chronic Skin Disease

Jim Krueger, MD PhD
The Rockefeller University
NY, NY
jgk@rockefeller.edu

My perspective

- Human skin is the body's barrier to the outside world of microbes (bacteria, viruses, fungi, worms, bugs, and other nasty substances)
- As such the skin is a complex tissue that has many protective immune functions—some are “natural” (innate immunity) and some are “learned with exposure” (acquired immunity)

Alternative Inflammatory States

- Homeostasis (normal appearing skin)– Immune cells and molecules are present, but kept in check by the “immune police” (negative regulators or immune checkpoints).
- Inflammation that is transient and then resolves (often fighting an infection)
- Inflammation that persists over time (often seen in skin diseases like psoriasis, eczema, and hidradenitis)

Protective vs. Pathogenic Immunity



Protective pathways can cause skin disease when activated persistently.
Causes can be unresolved infections, auto-inflammation, or auto-immunity.

Translational Science Approach

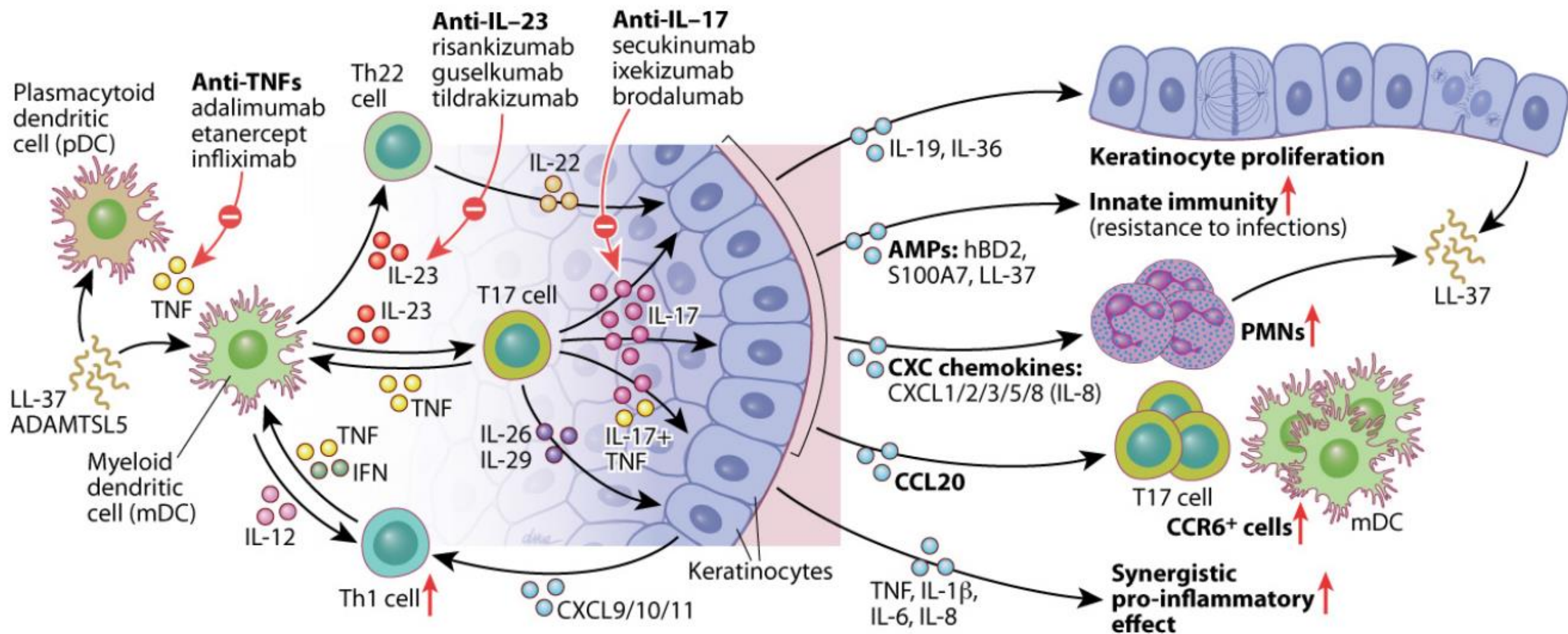
- Starts with the recognition that there is a skin disease with high need for better treatment
- Involves a partnership between patients with a disease and physician-scientists
- A component is “Bedside to Bench” research where possible disease mechanisms are discovered and studied in affected skin tissues or blood
- Another component is “Bench to Bedside” research where new possible therapies are tested and studied in clinical trials of patients with a specific skin disease

Best example of this approach:

Psoriasis vulgaris

- Psoriasis is a disease that affects 25 million people across North America and Europe
- 25 years ago had a small number of effective treatments that were available for short-term treatment (due to toxicity)
- Since, 2003 there has been FDA approval of 11 new drugs that treat psoriasis extremely well (good control in 90% of patients; no disease in ~50% of patients)

Basis for success in psoriasis: Disease maps of underlying immune pathways that can be targeted with specific inhibitors



Does the translational approach work in other skin diseases?

- Atopic eczema or atopic dermatitis— a disease even more common than psoriasis and also difficult to treat
- About a dozen years ago, creation of disease-associated immune maps started by Emma Guttman and collaborators at Rockefeller University, then continued at Mt. Sinai Medical Center.
- 1 year ago FDA approved first modern drug to treat AD and many “Bench to Bedside” clinical trials are recently completed or in progress (including some at Rockefeller University). This disease is about 10 years behind psoriasis, but it is catching up fast for new and improved treatments.

High Efficacy of IL-17 antagonists in Phase 3 Studies

- Secukinumab (anti-IL-17A) superior to ustekinumab in CLEAR study, 87% PASI75 in JUNCTURE study²
- Ixekizumab (anti-IL-17A) superior to etanercept in UNCOVER study, 90% PASI75 in best performing dosing group¹
- Brodalumab (anti-IL-17 Receptor, A subunit) superior to ustekinumab in AMAGINE-3 study,³ 86% PASI75 in AMAGINE-2 Study, best performing dose group⁴

Amgen has terminated brodalumab partnership with AstraZeneca. Brodalumab and ixekizumab are not currently licensed for therapeutic use


1. 'Lilly's Ixekizumab Superior to Etanercept and Placebo in Phase 3 Psoriasis Studies' press release available at: <https://investor.lilly.com/releasedetail.cfm?releaseid=867193>. Date accessed: May 2015. 2. Paul C et al. J Eur Acad Dermatol Venereol. 2014 [Epub ahead of print]. 3. 'Amgen and AstraZeneca announce positive results from second pivotal Phase III study of Brodalumab in patients with moderate-to-severe plaque psoriasis' press release. Available at: <http://www.astrazeneca.com/Media/Press-releases/Article/11112014--amgen-and-astrazeneca-announce-positive-results>. 'Amgen and AstraZeneca announce positive results from third and final pivotal Phase III study of Brodalumab in patients with moderate-to-severe

What about Hidradenitis suppuritiva (HS)?

- Now recognized as one of the most important skin diseases lacking treatments that will benefit most patients with this disease
- The Rockefeller Investigative Dermatology Group will begin studies in HS within the next 1-2 months with Translational Science approaches of “Bench to Bedside” and “Bedside to Bench,” including likely new therapeutic trials by this summer.
- We welcome your partnership with us in trying to understand, treat and maybe one day cure this important skin disease
- Contact: jgk@rockefeller.edu



Angie Parks-Miller, CCRP, CWCA
President & Founding Director, Hope for HS
National Coordinator of Advocacy & Support, HS Foundation
Clinical Research Manager, Investigator Initiated Studies,
Henry Ford Hospital, Department of Dermatology

- 
- *The importance of support and advocacy
 - *Awareness Events
 - *Resources

Hope for HS

- * Founded in 2013
- * Supported by Henry Ford Hospital, Detroit, MI
- * 501c3 non-profit organization
- * Grown by patient involvement
- * Mission to support, advocate, educate and promote research
- * Patient and medical community format

Why a Support Group ?

- * No replacement for human interaction
- * Sense of community, sense of belonging
- * Validation that only others with HS can provide
- * Increase disease awareness through education
- * Restore trust between HS Community and Medical Community

HS Impacts

- * Mental Health
- * Relationships – intimate / social
- * Socioeconomic
- * Activities of daily living

HS is a lonely and isolating disease

Risks of Isolation

*Holt-Lunstad, J, et al Perspect Psychol Sci. 2015 Mar*⁶

Loneliness and Social Isolation as Risk Factors for Mortality: A Meta-Analytic Review

Julianne Holt-Lunstad¹, Timothy B. Smith², Mark Baker¹, Tyler Harris¹, and David Stephenson¹

¹Department of Psychology and ²Department of Counseling Psychology, Brigham Young University

Perspectives on Psychological Science
2015, Vol. 10(2) 227–237
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sagepub.com/journalsPermissions.nav
DOI: 10.1177/1745691614568352
pps.sagepub.com
SAGE

- * Increased risk of mortality; over 3,000 subject studied
- * Comparable to well established risk factors; i.e., obesity
- * Loneliness = 26% increased risk of mortality
- * Social Isolation = 29% increased risk of mortality
- * Initial health status impacting stats

Increased Suicide Risk

Thorlacius et al JID 2018

ORIGINAL ARTICLE

Increased Suicide Risk in Patients with Hidradenitis Suppurativa



Linnea Thorlacius¹, Arnon D. Cohen^{2,3}, Gunnar H. Gislason^{4,5,6}, Gregor B.E. Jemec¹ and Alexander Egeberg⁷

- * Danish registry: 7,732 HS patients / general population over 4 million
- * Increased risk of completed suicide & antidepressant use
- * Suicide reported among support groups

Resilience

Kirby, Butt et al, JAMA Derm, 2017

JAMA Dermatology | Original Investigation

Association of Resilience With Depression and Health-Related Quality of Life for Patients With Hidradenitis Suppurativa

Joslyn S. Kirby, MD, MS, MEd; Melissa Butt, MPH; Solveig Esmann, MA; Gregor B. E. Jemec, MD, DMSc

- * Ability to adapt, recover after stress, trauma or tragedy
- * Higher resilience scores = smaller decrease HRQOL
- * Results support resilience moderates depression

Cultivate Resilience

- * **Make connections.** Good relationships with close family members, friends or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience. Some people find that being active in civic groups, faith-based organizations, or other local groups provides social support and can help with reclaiming hope. Assisting others in their time of need also can benefit the helper.

Psychology Today

- * Psychology Today is an easy-to-use resource to locate mental health professionals in the U.S. and Canada.
- * www.psychologytoday.com
- * ***Recommend search for professionals with chronic pain / sexual health experience***
- * Can search by location, insurance, therapy types, ie; CBT, talk therapy, etc



ADVOCACY

Change what **IS**, into what
SHOULD be

Advocate – Who?

- * Self: YOU are ALWAYS your best advocate
- * Others: trusted family member or friend(s) / support system

Self-Advocacy

- * Self-Advocacy:

- Refers to an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs or **rights**
- Involves making informed decisions and taking responsibility for those decisions

INVOLVE OTHERS

- * Although difficult, it is important to involve others in advocacy

Chinese proverb:

“*TELL* me and I will forget, *SHOW* me and I “may” remember, *INVOLVE* me and **I will understand.**”

- * Involving close family and friends in advocacy builds closer relationships
- * Increased awareness

Advocate – How?

- * **Educate** yourself and those closest to you about HS
 - Reliable and verifiable sources of information
 - www.hs-foundation.org
 - Learn about treatment options, understand the reasons behind each
 - participate in support groups, on line or in person
 - Continue to participate even if you are feeling well
 - Family and friends to participate in awareness activities

Be Prepared

- * Be prepared for medical appointments
 - Suggestion: Binder with all pertinent records
 - Note book, prepared questions, record answers
 - **ASK QUESTIONS UNTIL SATISFIED**

ASK!

- * How do you communicate questions outside of an appointment? VERY IMPORTANT
- * How should you handle a flare after hours, holidays?
- * How should you manage pain? What are your options?
- * How are comorbidities managed? Example: metabolic syndrome – endocrinology?
- * How are mental health impacts/quality of life impacts managed?

Awareness Events

*June 4th-10th, 2018 HS
Awareness Week



*State Proclamations



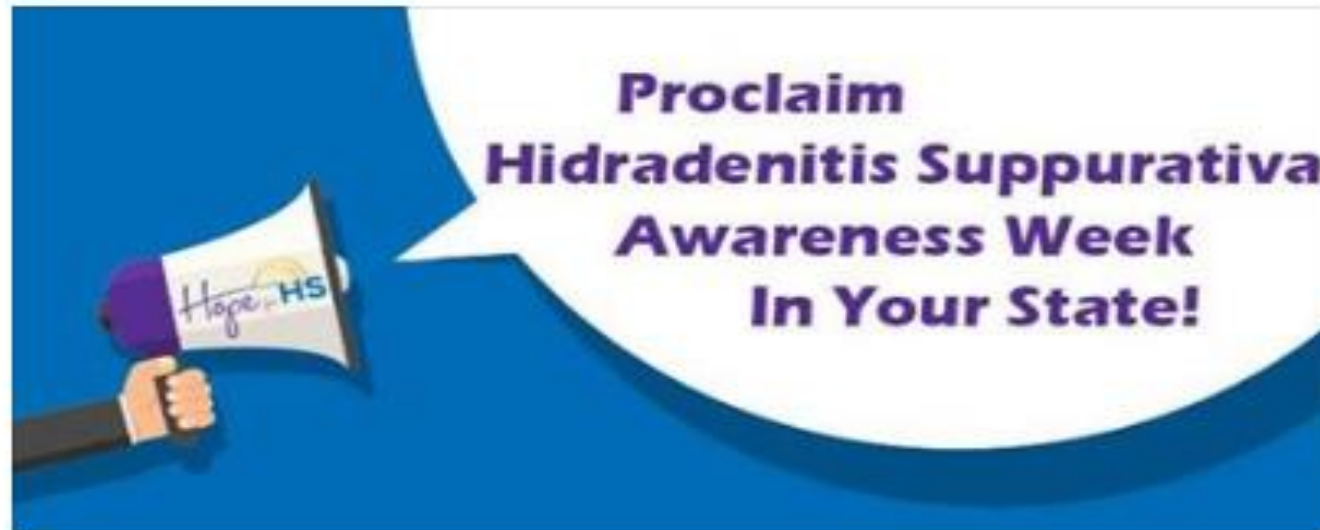
Hope for HS

Published by Hope for HS (?) · March 22 · 🌐



Would you like your state government to recognize Hidradenitis Suppurativa Awareness Week? Our letter writing campaign is underway, and we are here to help!

Contact Hope for HS to get the free support and information you need to ask your governor to proclaim Hidradenitis Suppurativa Awareness Week in your state.



Hope for HS

Nonprofit Organization

Send Message



To date, 9 U.S. State Governor's
have issued Proclamations



Proclamation By the Governor of Alabama

WHEREAS, Hidradenitis Suppurativa (HS) is a chronic, debilitating, non-contagious, inflammatory skin condition for which there is no known cure; and

WHEREAS, HS is characterized by clusters of abscesses or subcutaneous boil-like lesions that most commonly affect the underarms, under the breasts, inner thighs, groin and buttocks. Outbreaks of HS are painful and may persist for years with interspersed periods of inflammation. This process often forms open wounds that do not heal and may lead to significant scarring, disfigurement, reduced range of motion and chronic pain; and

WHEREAS, when all stages of disease are considered, it is estimated that one to four percent of the world's population is affected by HS, and experience an average delay of seven years for a proper diagnosis; and

WHEREAS, patients with HS often endure a severely diminished quality of life. Understanding and compassion for those with HS from family, friends, medical providers and the public at large is vital; and

WHEREAS, Hidradenitis Suppurativa Awareness Week provides an opportunity to increase awareness, correct misconceptions, recognize the struggles of those affected and shorten the delay in diagnosis;

NOW, THEREFORE, I, Kay Ivey, Governor of Alabama, do hereby proclaim June 4-10, 2018, as

Hidradenitis Suppurativa Awareness Week

in the State of Alabama.



Given Under My Hand and the Great Seal of the
Office of the Governor at the State Capitol in the City
of Montgomery on the 1st day of May 2018.

Kay Ivey
Kay Ivey, Governor

STATE OF ARKANSAS EXECUTIVE DEPARTMENT PROCLAMATION

TO ALL TO WHOM THESE PRESENTS COME -- GREETINGS

WHEREAS: Hidradenitis Suppurativa (HS) is a chronic, non-contagious condition that can be debilitating and potentially life-altering and for which there is no known cure; and

WHEREAS: HS is characterized by clusters of abscesses and painful lesions that most commonly affect the underarms, under the breasts, inner thighs, groin, and buttocks; and

WHEREAS: As many as 1-4 percent of the world's population is affected by HS, and according to recent research, those affected by HS experience an average delay of seven years for a proper diagnosis; and

WHEREAS: Patients with HS may endure a severely diminished life and can benefit from a compassionate group of family, friends, medical providers, and the public at large; and

WHEREAS: Hidradenitis Suppurativa Awareness Week provides an opportunity to increase awareness, correct misconceptions, recognize the struggle of those affected, and shorten the delay of diagnosis;

NOW, THEREFORE, I, ASA HUTCHINSON, Governor of the State of Arkansas, by virtue of the authority vested in me by the laws of the State of Arkansas, do hereby proclaim June 4th through June 10th, 2018, as

HIDRADENITIS SUPPURATIVA (HS) AWARENESS WEEK IN ARKANSAS

IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Arkansas to be affixed this 27th day of April, in the year of our Lord 2018.



Asa Hutchinson
Asa Hutchinson, Governor

Attest:

Mark Martin
Mark Martin, Secretary of State

STATE of WISCONSIN



OFFICE of the GOVERNOR

Proclamation

WHEREAS hidradenitis suppurativa (HS) is a chronic, debilitating, non-contagious life-altering, and potentially life-threatening illness for which there is no known cure; and

WHEREAS an estimated one-to-four percent of the world's population is affected by HS, postpubescent individuals are more likely to exhibit symptoms, and according to recent research, those affected by HS experience an average delay of seven years for a proper diagnosis; and

WHEREAS patients with HS often endure a severely diminished quality of life, and understanding and compassion for HS patients from family, friends, medical providers, and the public is vital; and

WHEREAS Hidradenitis Suppurativa Awareness Week provides an opportunity to increase awareness, correct misconceptions, recognize the struggles of those affected, and shorten the delay in diagnosis;

NOW, THEREFORE, I, Scott Walker, Governor of the State of Wisconsin, do hereby proclaim June 4 – 10, 2018 as

HIDRADENITIS SUPPURATIVA AWARENESS WEEK

throughout the State of Wisconsin and I commend this observance to all of our citizens.



IN TESTIMONY WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Wisconsin to be affixed. Done at the Capitol in the City of Madison this 9th day of May 2018.


SCOTT WALKER
GOVERNOR

By the Governor:


DOUGLAS LA FOLLETTE
Secretary of State



John Bel Edwards
GOVERNOR

Proclamation

WHEREAS,

Hidradenitis Suppurativa (HS) is a chronic, debilitating, non-contagious, inflammatory skin condition for which there is no known cure; and

WHEREAS,

HS is characterized by clusters of abscesses or subcutaneous boil-like lesions that most commonly affect the underarms, under the breasts, inner thighs, groin and buttocks; and

WHEREAS,

outbreaks of HS are painful and may persist for years with interspersed periods of inflammation; and

WHEREAS,

this process often forms open wounds that do not heal and may lead to significant scarring, disfigurement, reduced range of motion and chronic pain; and

WHEREAS,

it is estimated that one to four percent of the world's population is affected by HS, and experience an average delay of seven years for a proper diagnosis; and

WHEREAS,

patients with HS often endure a severely diminished quality of life; and

WHEREAS,

understanding and compassion for those with HS from family, friends, medical providers and the public at large is vital; and

WHEREAS,

Hidradenitis Suppurativa Awareness Week provides an opportunity to increase awareness, correct misconceptions, recognize the struggles of those affected and shorten the delay in diagnosis.

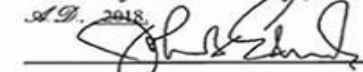
NOW, THEREFORE,

I, John Bel Edwards, Governor of the State of Louisiana, do hereby proclaim June 4-10, 2018 as

HIDRADENITIS SUPPURATIVA AWARENESS WEEK
in the State of Louisiana.



In Witness Whereof, I have hereunto set my hand officially and caused to be affixed the Great Seal of the State of Louisiana, at the Capitol, in the City of Baton Rouge, on this 4th day of June
A.D. 2018.


Governor of Louisiana



STATE OF TENNESSEE
PROCLAMATION
BY THE GOVERNOR

WHEREAS, Hidradenitis Suppurativa (HS) is a chronic, non-contagious condition that can be debilitating and potentially life-altering and for which there is no known cure; and

WHEREAS, HS is characterized by clusters of abscesses or subcutaneous boil-like lesions that most commonly affects the underarms, under the breasts, inner thighs, groin, and buttocks; and

WHEREAS, outbreaks of HS are painful and may persist for years with interspersed periods of inflammation, potentially creating open wounds that do not heal and may lead to significant scarring; and

WHEREAS, as many as 1-4 percent of the world's population is affected by HS, and postpubescent individuals are more likely to exhibit symptoms; and

WHEREAS, according to recent research, those affected by HS experience an average delay of seven years for a proper diagnosis; and

WHEREAS, patients with HS may endure a severely diminished quality of life, and thus deserve understanding and compassion from family, friends, medical providers and the public at large; and

WHEREAS, Hidradenitis Suppurativa Awareness Week provides an opportunity to increase awareness, correct misconceptions, recognize the struggles of those affected, and shorten the delay in diagnosis;

NOW, THEREFORE, I, Bill Haslam, Governor of the State of Tennessee, do hereby proclaim the week of June 4-10, 2018 as

Hidradenitis Suppurativa Awareness Week

in Tennessee and encourage all citizens to join me in this worthy observance.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the official seal of the State of Tennessee to be affixed at Nashville on this ninth day of April, 2018.

Bill Haslam

Governor

Lee Vincent

Secretary of State



STATE OF MICHIGAN

CERTIFICATE OF PROCLAMATION

ON BEHALF OF THE PEOPLE OF MICHIGAN

I, Rick Snyder, governor of Michigan, do hereby proclaim
June 4-10, 2018

**HIDRADENITIS SUPPURATIVA
AWARENESS WEEK**

WHEREAS, Hidradenitis Suppurativa (HS) is a chronic, debilitating, non-contagious skin disease with severe quality of life impact, for which there is no known cure; and,

WHEREAS, Michigan is home to the largest HS clinic in the United States, with over 1,300 patients in the Department of Dermatology at Henry Ford Hospital, in Detroit; and,

WHEREAS, Hope for HS, supported by Henry Ford Hospital Department of Dermatology and by the Hidradenitis Suppurativa Foundation, was founded in Detroit in 2013 with a mission to educate, advocate and support; and,

WHEREAS, recent research shows that those with HS experience an average of a 7 year delay to achieve a diagnosis. This is due in part to the lack of awareness surrounding this disease, both by those affected and by medical providers; and,

WHEREAS, during this week we join with the members of Hope for HS and the entire HS community to raise awareness of this disease, educate the community to recognize the characteristics of HS, correct misconceptions, and help reduce the amount of time it takes to receive the appropriate diagnosis and treatment;

NOW, THEREFORE, I, Rick Snyder, governor of Michigan, do hereby proclaim June 4-10, 2018 as Hidradenitis Suppurativa Awareness Week in Michigan.



Rick Snyder

Rick Snyder
Governor





BY THE GOVERNOR OF THE STATE OF GEORGIA

A PROCLAMATION

HIDRADENITIS SUPPURATIVA AWARENESS WEEK

WHEREAS: Hidradenitis suppurativa (HS) is a chronic, debilitating, non-contagious, and potentially life-threatening illness for which there is no known cure; and

WHEREAS: HS is an orphan disease characterized by clusters of abscesses or subcutaneous boil-like lesions that most commonly affect skin under the arms, under the breasts, behind the ears, or around the inner thighs, groin, or buttocks; and

WHEREAS: Outbreaks of HS are painful and may persist for years with interspersed periods of inflammation. Such outbreaks and inflammation may form wounds that do not heal, leading to scarring; and

WHEREAS: An estimated 1 to 4 percent of the world's population is affected by HS, and postpubescent individuals are the most likely to exhibit symptoms; and

WHEREAS: According to recent research, proper diagnoses for HS are delayed by seven years on average. Though medicines and surgeries are available to alleviate symptoms and pain, they are not always effective in treatment; and

WHEREAS: Patients with HS often endure a diminished quality of life. To best support those affected by HS, it is important for family members, friends, medical providers, and the community at large to better understand the disease and its symptoms; and

WHEREAS: Hidradenitis Suppurativa Awareness Week provides an opportunity for organizations including Hope for HS to increase awareness, correct misconceptions, recognize the struggles of those affected, and shorten the delay in diagnosis; now

THEREFORE: I, NATHAN DEAL, Governor of the State of Georgia, do hereby proclaim June 4-10, 2018, as HIDRADENITIS SUPPURATIVA AWARENESS WEEK in Georgia.

In witness thereof, I have hereunto set my hand and caused the Seal of the Executive Department to be affixed this 2nd day of April in the year of our Lord two thousand eighteen.



Nathan Deal
GOVERNOR

ATTEST
Chris M. Pety
CHIEF OF STAFF

by Governor Jim Justice

Whereas, Hidradenitis Suppurativa (HS) is a chronic, debilitating, non-contagious, inflammatory skin condition for which there is no known cure; and

Whereas, outbreaks of HS are painful and may persist for years with interspersed periods of inflammation; and

Whereas, when all stages of disease are considered, it is estimated that 1-4% of the world's population is affected by HS and experience an average delay of seven years for a proper diagnosis; and

Whereas, patients with HS often endure a severely diminished quality of life; understanding and compassion for those with HS from family, friends, medical providers and the public at large is vital; and

Whereas, *Hidradenitis Suppurativa Awareness Week* provides an opportunity to increase awareness, correct misconceptions recognize the struggles of those affected, and shorten the delay in diagnosis.

Now, Therefore, Be it Resolved that I, Jim Justice, Governor of the Great State of West Virginia, do hereby proclaim *June 4-10, 2018* as:

Hidradenitis Suppurative Awareness Week

in the Mountain State and encourage all citizens to join me in this observance.

In Witness Whereof, I have hereunto set my hand and caused the Great Seal of the State of West Virginia to be affixed.

Done at the Capitol, City of Charleston, State of West Virginia, this the Fifteenth day of May, in the year of our Lord, Two Thousand Eighteen, and in the One Hundred Fifty-Fifth year of the State.



Jim Justice
Jim Justice
Governor

By the Governor:

Mac Warner
Mac Warner
Secretary of State

#BringHStoLight

A person is shown from the chest up, holding a lit sparkler. The sparkler is bright and has many sparks flying out. The person's face is partially visible in the background, looking down at the sparkler. The overall scene is dark, with the light from the sparkler illuminating the person's face and the text on the left.

BRING HIDRADENITIS SUPPURATIVA TO LIGHT

JOIN US SAT., JUNE 9TH FOR A CANDLELIGHT VIGIL TO RAISE AWARENESS OF HIDRADENITIS SUPPURATIVA (HS), THE THIRD MOST PAINFUL DISEASE IN THE WORLD. WE'RE RAISING AWARENESS TO FOSTER COMPASSION AND UNDERSTANDING AND TO PROMPT THE MEDICAL COMMUNITY TO SEEK A CURE FOR THIS DREADED ILLNESS. WE ARE ALSO HONORING THOSE WHO HAVE SUCCEDED TO HS-RELATED COMPLICATIONS. PLEASE HELP US HONOR THEM BY LIGHTING A CANDLE. THANK YOU.

For more information:

Also visit www.penspen.wixsite.com/bringhstolight

June 9th, 2018

BRING HIDRADENITIS SUPPURATIVA TO LIGHT

JOIN US ON SATURDAY, JUNE 9

FOR A CANDLELIGHT VIGIL TO RAISE HS AWARENESS

MEMORIAL PARK

ROYAL OAK, MICHIGAN

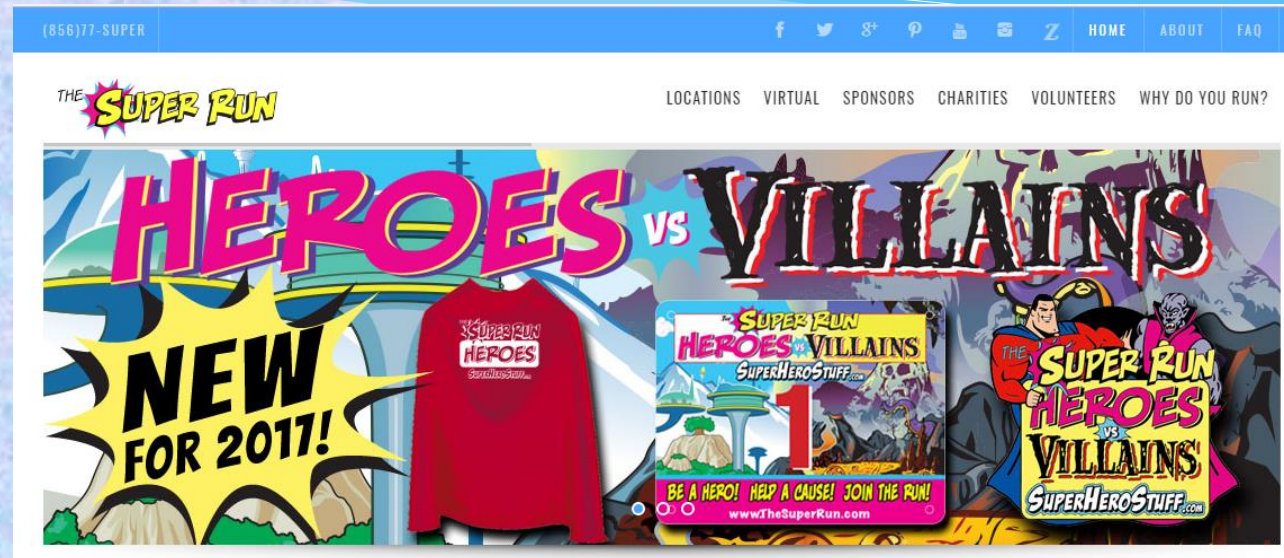
8PM







2017



- * Super Hero 5 K
- * Ann Arbor, MI
- * Patients, families, medical community
- * Charity partner
- * Revenue of over \$300



Continue

- * Hope for HS will continue to grow
- * Support patients and caregivers
- * Seek patient input
- * Conduit for patients and medical community to work together
- * Advocate
- * We need ALL of you

Find a HS Specialty Clinic

www.hs-foundation.org/hs-specialty-clinics/

- * HS Foundation, 21 clinics listed



The screenshot shows the HS Foundation website. The header includes the logo for Hidradenitis Suppurativa Foundation, Inc., a 'Sign up to receive information!' button, and a 'DONATE' button. A navigation menu lists: SHSA, About, HS/AI Information, Treatments, Advocacy & Support, Research, Find a Clinic, and Donate. The main content area features a large blue geometric pattern. Below this, the 'Find a Physician' section lists 'HS Specialty Clinics'. The 'Hidradenitis Suppurativa Specialty Clinics' section includes a call to action for medical providers to email executivedirectorhsf@gmail.com. Three clinics are listed:

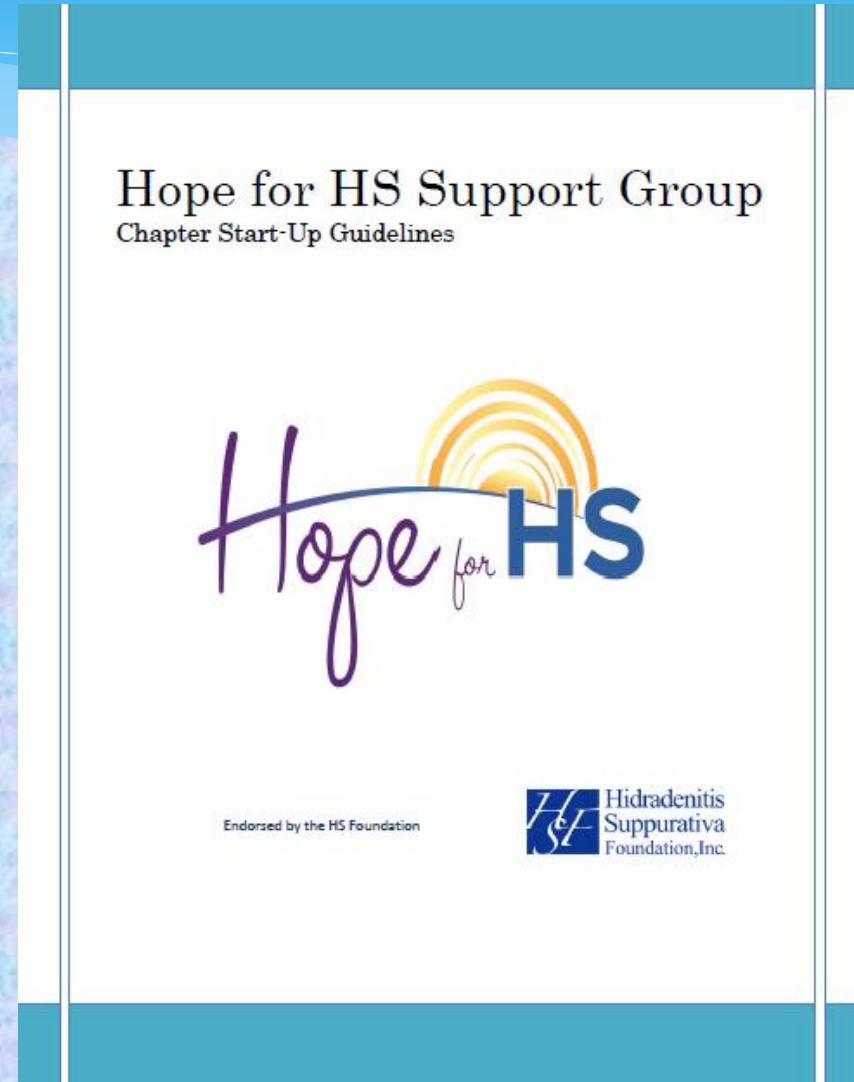
University of Cincinnati, Department of Dermatology	Harvard Medical Faculty Physicians at Beth Israel Deaconess Medical Center, Inc.	Temple University Department of Dermatology
Ali Alikhan, MD	Alexa Boer Kimball, MD	Lauren Orenstein, MD
<ul style="list-style-type: none">Cincinnati, OhioAppointments: 513-558-6242	<ul style="list-style-type: none">Boston, Massachusetts	<ul style="list-style-type: none">Philadelphia, PennsylvaniaAppointments: 215-707-3376

Start a Chapter!

Contact:

amiller5@hfhs.org

sandra@hopeforhs.org



Thank you

- *Sandra Guilbault
- *Mukul Sharma
- *The Rockefeller University
- *HS Community & HS Medical Community

THE ROCKEFELLER UNIVERSITY



Shedding light on hidradenitis suppurativa (HS)

May 21, 2018

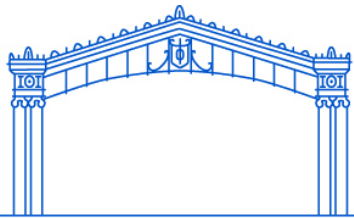
Carson Family Auditorium

Questionnaire for feedback

Webchat questions

Get involved!

Thank you!



THE ROCKEFELLER UNIVERSITY HOSPITAL

CENTER FOR CLINICAL AND TRANSLATIONAL SCIENCE



Hidradenitis Suppurativa
Foundation (HSF)
hs-foundation.org



Hope for HS
hopeforhs.org



Canadian Hidradenitis
Suppurativa Foundation
(CHSF)
hsfoundation.ca/en/home



Symposium on Hidradenitis
Suppurativa Advances (SHSA)
October 12-14th, 2018
Toronto, Canada
hs-symposium.org



Dr. Loo