

REMEMBERING ARISTOTLE'S BALANCE

TEACHING CHILD NEUROLOGY IN A TIME OF GENOMICS,
MASS MIGRATION AND GLOBAL UPHEAVAL

DAVID K. URION, M.D., FAAN
CHARLES F. BARLOW CHAIR
DIRECTOR OF EDUCATION AND RESIDENCY
TRAINING PROGRAMS
DEPARTMENT OF NEUROLOGY
BOSTON CHILDREN'S HOSPITAL
HARVARD MEDICAL SCHOOL

DISCLOSURES

- I HAVE NO FINANCIAL DISCLOSURES RELEVANT TO THIS PRESENTATION
- IN ADDITION TO BEING CHILD NEUROLOGIST, I AM ALSO A MEDICAL ETHICIST AND MY TRADITION OF CHOICE IS VIRTUE ETHICS

DISCLOSURES

- I HAVE SPENT THE LAST FOUR DECADES PRACTICING CHILD NEUROLOGY, MOSTLY IN THE DOMAIN OF CHILDREN WITH SIGNIFICANT NEURODEVELOPMENTAL DISORDERS
- I HAVE ALSO SPENT THOSE SAME FOUR DECADES TEACHING CHILD NEUROLOGY



OBJECTIVES

- TO CONSIDER OUR CURRENT MOMENT IN THE CONTINUING EVOLUTION OF CHILD NEUROLOGY
- TO CONSIDER THE OPPORTUNITIES AND THE CHALLENGES THAT NEW AND POWERFUL TECHNOLOGIES SUCH AS GENOMIC ASSESSMENT OFFER US
- TO CONSIDER THE PROFESSION IN THE CONTEXT OF THE CURRENT MASS MIGRATIONS WE SEE
- TO CONSIDER THE PROFESSION IN THE CONTEXT OF CURENT GLOBAL UPHEAVAL

AT A DEEPER LEVEL

- HOW CAN WE REMAIN A FORCE THAT ADVOCATES FOR THE FUNDAMENTAL HUMANITY OF THE PATIENTS AND FAMILIES WE SERVE?
- HOW CAN WE INFLUENCE THE PUBLIC DIALOGUE IN A TIME THAT IS INCREASINGLY MEAN-SPIRITED

A CAUTIONARY OBSERVATION

- CHILD NEUROLOGY AND PSYCHIATRY IN THE LATE WEIMAR GERMAN REPUBLIC WERE THE MOST ADVANCED IN THE WORLD
- THE WORLD CAME TO TRAIN THERE
- TECHNICAL EXCELLENCE AND GENERAL SOCIETAL LIBERALISM DID NOT SAVE THEM FROM INTELLECTUALLY SUPPORTING AND ULTIMATELY COLLABORATING WITH THE HORRORS OF THE NATIONAL SOCIALIST ENTERPRISE

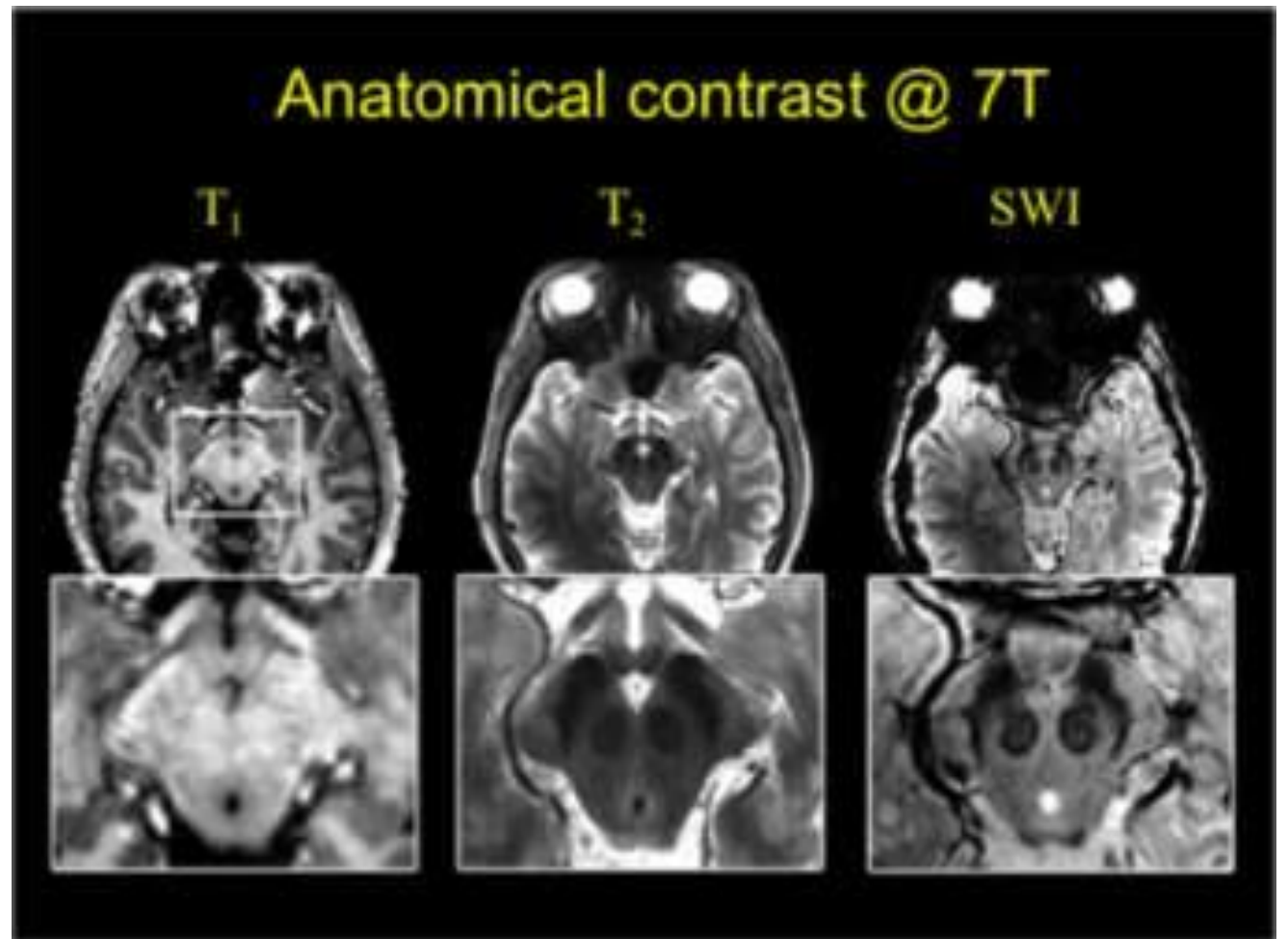
IN OTHER WORDS

- BY STUDYING HISTORY AND CONTEMPLATING THE PRESENT, CAN WE CONTRIBUTE TO A BETTER FUTURE?

OUR CURRENT MOMENT

- “IT WAS THE BEST OF TIMES, IT WAS THE WORST OF TIMES”
- OUR CURRENT MOMENT IS IN THE MIDST OF AN EXTRAORDINARY EXPLOSION OF NEUROSCIENCE KNOWLEDGE
- THAT KNOWLEDGE HAS BEEN HARNESSSED IN EQUALLY EXTRAORDINARY WAYS

IMAGING





WHOLE EXOME SEQUENCING

AND OTHER RELATED
TECHNOLOGIES

POWERFUL GENETIC TREATMENTS

- NUSINERSEN AND OTHER ANTI-SENSE OLIGONUCLEOTIDES





BESPOKE THERAPY

- DEVELOPING A TREATMENT FOR A SPECIFIC INDIVIDUAL'S DISEASE SIGNATURE
- THE ULTIMATE IN PERSONALIZED MEDICINE

ALL OF THESE NEW
THERAPIES COME
WITH A COST

- THERE IS THE LITERAL COST : NUSINERSEN HAS A LISTING PRICE OF USD 750,000 FOR THE FIRST YEAR OF TREATMENT, AND USD 350,00 EVERY YEAR THEREAFTER

ALL THESE THERAPIES COME WITH QUESTIONS

- WHO BENEFITS? HOW DO WE DECIDE ACCESS TO THESE TREATMENTS?
- WHO DETERMINES THE RESEARCH STRATEGY? IS THIS DRIVEN BY THE GOVERNMENT? LEARNED ORGANIZATION? INDUSTRY? FAMILIES?

ALL THESE THERAPIES CHANGE THE WAY MEDICINE IS PRACTICED

- HOW DO WE FUNCTION IN A WORLD IN WHICH CLINICAL ACUMEN AND YEARS OF PRACTICE MAY BE DISPLACED BY GENETIC TESTING?
- WHAT DOES THIS DO TO THE ART OF WHAT WE PRACTICE, AND HOW PATIENTS AND THEIR FAMILIES INTERACT WITH US?

ALL THESE THERAPIES CHANGE OUR RELATIONSHIPS

- MEDICINE IS BECOMING COMMODIFIED
- PATIENTS ARE BECOMING CONSUMERS AND PHYSICIANS ARE BECOMING PROVIDERS
- THIS CHANGES HOW WE RELATE TO ONE ANOTHER

DEDAN KIMATHI

- BEFORE A PERSON GIVES UP HIS OLD WAYS AND HIS COMMON CUSTOMS, THEY SHOULD MAKE SURE THEY HAVE SOMETHING OF VALUE TO REPLACE THEM



HOW BEST TO CONSIDER THIS?

WE CAN THINK ABOUT AN ETHICAL ANALYSIS

- WHILE THERE ARE MANY APPROACHES TO MEDICAL ETHICS (DEONTOLOGIC, CONSEQUENTIALIST, VIRTUE, NARRATIVE, AND OTHER FORMS OF ETHICAL TRADITION) MOST US MEDICAL ETHICS SERVICES AND HOSPITAL-BASED ETHICS SERVICES RELY HEAVILY ON A PRINCIPLISM
- FIRST DELINEATED BY GILLON AND RUDDICK IN THE LATE 20TH CENTURY IN THE UK, FURTHER DEVELOPED BY BEAUCHAMP AND CHILDRESS HERE IN THE US

PRINCIPLISM

- AUTONOMY
- BENEFICENCE
- NON-MALEFICENCE
- JUSTICE

THIS IS NOT A HIERARCHY

- IN ANY GIVEN SITUATION, ONE OF THESE PRINCIPLES MAY BE MORE IMPORTANT THAN THE OTHERS
- FOR EXAMPLE, IN THE US WE FEEL STRONGLY THAT PARTICIPATION IN RESEARCH SHOULD BE VOLUNTARY, WELL-INFORMED, AND REFLECT THE INDIVIDUAL'S EXISTENCE AS AN AUTONOMOUS MORAL BEING ENDOWED WITH FREE CHOICE

IN PEDIATRIC SETTINGS

- THIS IS FURTHER CONFOUNDED BY THE QUESTION OF WHO SPEAKS FOR THE MINOR OR DEPENDENT OFFSPRING?
- WE HAVE TENDED TO GIVE PARENTS WIDE DEFERENCE IN DECISION MAKING AROUND MEDICAL CARE, AS WELL AS THE CHOICE TO HAVE THEIR MINOR OR DEPENDENT OFFSPRING PARTICIPATE OR DECLINE TO PARTICIPATE IN RESEARCH
- WE HAVE EXCLUDED CHILDREN, BY AND LARGE, FROM PARTICIPATION IN CERTAIN KINDS OF RESEARCH BY MAKING THEM A PRIVILEGED CLASS



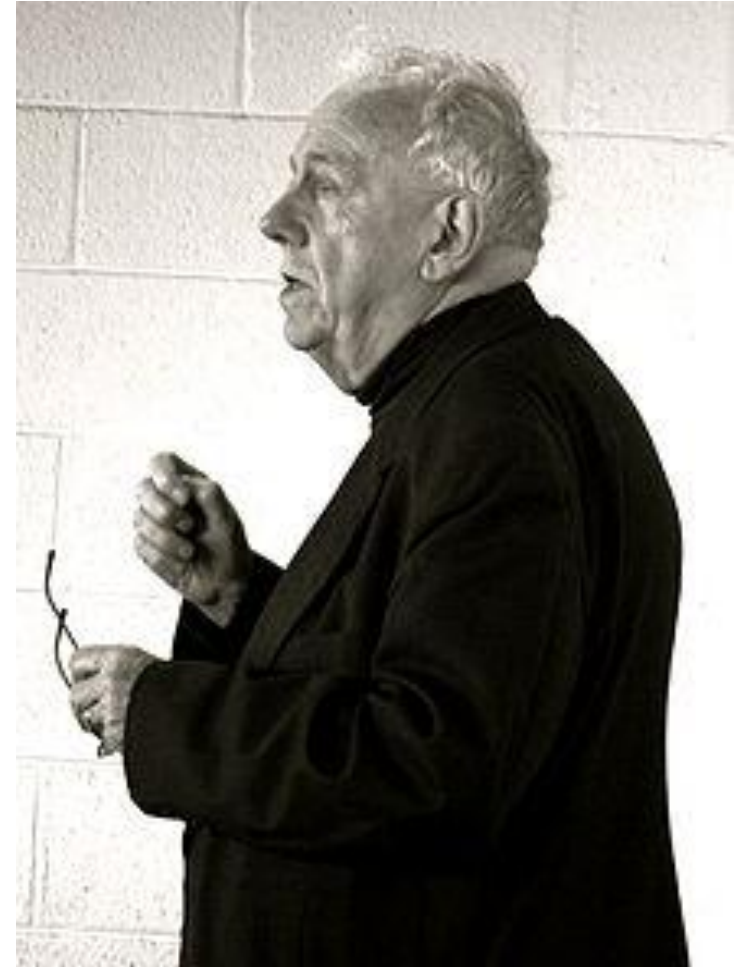
THAT IS

- WE INVOKE IDEAS OF NON-MALEFICENCE AND BENEFICENCE TO CURTAIL AUTONOMY

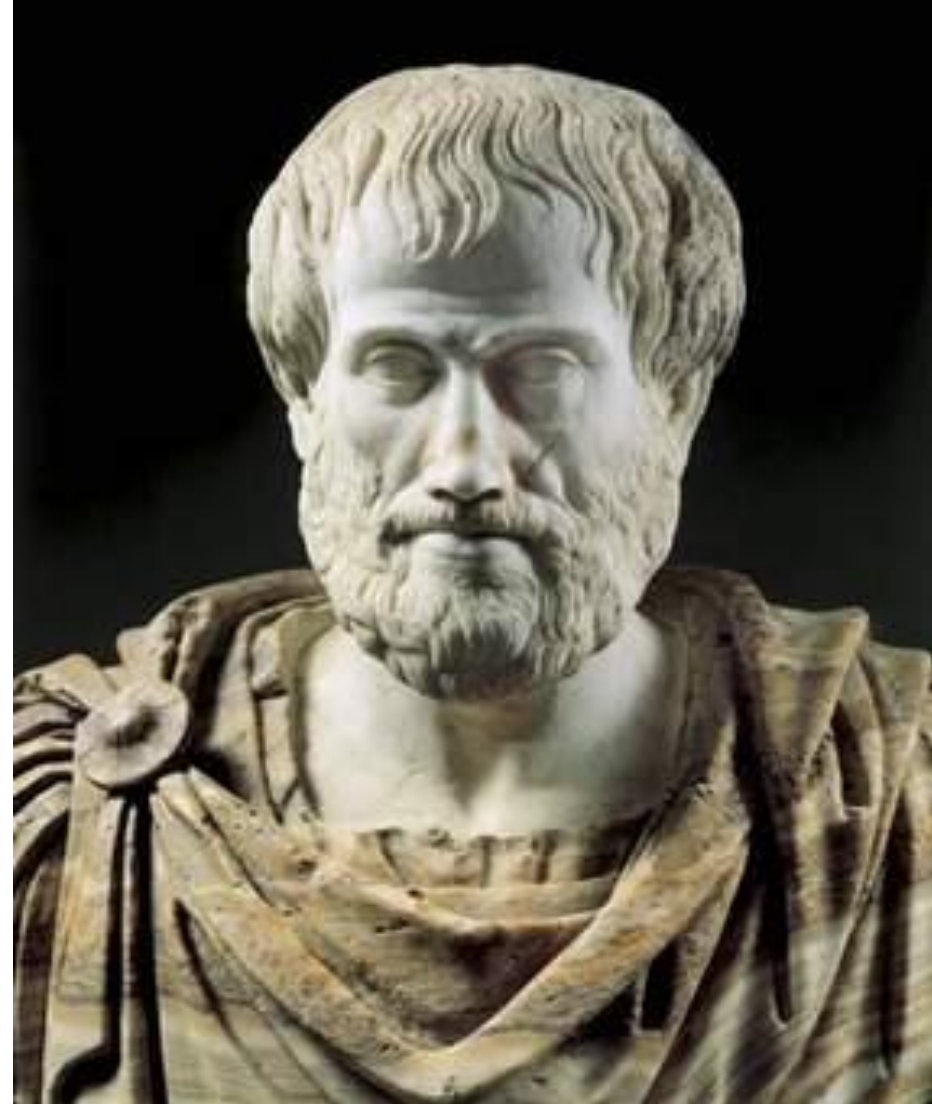
BUT THIS HAS PROVED DIFFICULT

IN A WORLD OF MULTIPLE COMPETING
CULTURAL MODELS AND NORMS

WHOSE JUSTICE? WHICH
RATIONALITY?



REMEBERING
ARISTOTLE'S
BALANCE





CENTRAL TENETS

- HUMANS-AS-THEY-ARE, NOT HUMANS-AS-THEY-SHOULD-BE
- RULES DERIVE FROM VIRTUES, WHICH ARE A BALANCE POINT BETWEEN TWO POLES :
GENEROSITY IS THE BALANCE POINT BETWEEN MISERLINESS AND PROFLIGACY
- WE EXIST IN THE CONTEXT OF A SOCIETY AND RULES ARE ONLY MEANINGFUL IN THAT CONTEXT

SO WHAT ON EARTH DOES THIS HAVE TO
DO WITH CHILD NEUROLOGY IN THE
CURRENT MOMENT?



WE STRUGGLE TO REMEMBER A BALANCE

- WE NEED TO INTERACT
WITH PATIENTS AND NOT
COMPUTERS



WE NEED TO EXAMINE PATIENTS
AND NOT MOVE TOO QUICKLY
TO GENETIC TESTING

RESOURCES ARE FINITE

LIFE IS SHORT AND THE ART IS LONG





WE NEED TO
REDISCOVER
THE JOY IN
OUR
PRACTICE

- SO WE CAN CONVINCE ANOTHER
GENERATION TO JOIN US

WE NEED TO REMEMBER THAT
MORE UNITES US THAN
SEPARATES US

- TOO MANY FORCES ATTEMPT TO BUILD WALLS
- WE WERE AND CAN STILL BE A PROFOUNDLY TRANSNATIONAL DISCIPLINE



WE LIVE UNDER
THE
FUNDAMENTAL
EFFECTS OF
CLIMATE CRISIS

MASS MIGRATION
IS THE NEW
NORMAL

THIS MEANS

- THAT OUR WORLD GOT MUCH SMALLER
- I NEED TO TEACH OUR RESIDENTS ABOUT DISORDERS THAT WE ONCE THOUGHT “EXOTIC” OR “TROPICAL”
- DENGUE HAS RE-ESTABLISHED ITSELF IN THE CONTINENTAL US
- WEST NILE VIRUS BECAME ESTABLISHED ACROSS THE CONTINENT IN < 48 MONTHS

THIS MEANS

- WE ARE ALL DEPENDENT UPON THE KNOWLEDGE WE ALL HAVE
- ALL OF US ARE SMARTER THAN ANY OF US

AN EXAMPLE

- WE WERE FACED A FEW YEARS AGO WITH TWO CHILDREN EVACUATED TO OUR HOSPITAL WITH A SYNDROME THAT PROVED TO BE ACUTE ARSENIC INTOXICATION
- A BEVERAGE HAD BEEN PREPARED IN A PLASTIC JUG THAT HAD CONTAINED HERBICIDE
- WE HAD NO EXPERIENCE WITH THIS

A COLLEAGUE

- DID EPIDEMIOLOGIC STUDIES IN BANGLADESH
- KNEW THAT THERE WAS A HUGE PROBLEM OF ACUTE AND CHRONIC ARSENIC INTOXICATION IN BANGLADESH – DOWNSTREAM FROM EVERYTHING
- KNEW THE PEOPLE WHO TREATED THIS AND WAS ABLE TO CONNECT US

THIS WASN'T A GOOGLE SEARCH

- THIS WAS A RELATIONSHIP

THIS IS NO LONGER ISOLATED

- THE MASS MIGRATION OF LARGE POPULATIONS BRINGS WITH IT A VARIETY OF DISORDERS AND DISEASES FOR WHICH WE HAVE NOT TRADITIONALLY PREPARED
- RETREATING FROM TRANSNATIONAL COLLABORATION MAKES US THE POORER AND THE MORE IGNORANT

IN A WORLD TURNED UPSIDE DOWN

- WE CAN BE VOICES FOR SANITY, REASON
- WE CAN REMEMBER ARISTOTLE'S BALANCE

OUR CHILEAN EXPERIENCE

- THROUGH A PERSONAL RELATIONSHIP WITH A CHILEAN CHILD NEUROLOGIST WHO TRAINED IN METABOLISM AND GENETICS AT BOSTON CHILDREN'S HOSPITAL, I WAS INVITED TO SPEAK IN CHILE
- WE RETURNED THE INVITATION
- WE WERE BOTH TRAINING DIRECTORS

A COLLABORATION GREW

- RESIDENTS FROM OUR PROGRAM WENT DOWN TO CHILE FOR A MONTHLONG ROTATION
- CHILEAN RESIDENTS CAME UP TO ATTEND A WEEK-LONG COURSE WE GIVE, AND TO SPEND 2 – 3 WEEKS IN OUR SUBSPECIALTY CLINICS

A GENERAL PRINCIPLE OF EXCHANGE PROGRAMS

- FAIR IS NOT EQUAL IS NOT IDENTICAL
- WHAT DOES EACH NEED, WHT CAN EACH OFFER?

15 YEARS LATER

- 56 CHILEAN CHILD NEUROLOGISTS HAVE COME TO VISIT US
- 6 OF OUR RESIDENTS HAVE SPENT A MONTH IN CHILE
- WE EXCHANGE FACULTY VISITS ANNUALLY
- WE HAVE A MONTHLY JOINT VIDEO CONFERENCE, PRESENTING EACH OTHER CASES AND PRESENTATIONS IN AN ALTERNATING FASHION
- RESIDENT DRIVEN AND RUN
- THEIR RESPECTIVE WORLDS ARE NOW MORE CONNECTED

INVITING A PARTNERSHIP



BETWEEN OUR INSTITUTIONS

WHAT IF WE ENGAGED IN A SIMILAR WAY?

- 1ST DEPARTMENT OF PEDIATRICS
- HIPPOKRATIO GENERAL HOSPITAL
- ARISTOTLE UNIVERSITY
- THESSALONIKI, GREECE
- DEPARTMENT OF NEUROLOGY
- BOSTON CHILDREN'S HOSPITAL
- HARVARD UNIVERSITY
- BOSTON, MA

WE'VE ALREADY BEGUN

- WE HAVE HOSTED DR. ZAFEIRIOU SEVERAL TIMES
- I AM HONORED TO BE YOUR GUEST
- WHAT IF WE TOOK THIS TO THE NEXT STEP – SHARED CONFERENCES, OTHER FACULTY AND TRAINEE EXCHANGES ?

I THINK WE WOULD BOTH BE
ADVANTAGED

- I THINK WE WOULD REDRESS SOME IMBALANCE

A VOICE FOR REASON IN A WORLD OF
MALEVOLENT TWEETS AND ISOLATIONIST
VITRIOL



LET'S GET STARTED

THANKS FOR YOUR KIND INDULGENCE

- DAVID.URION@CHILDRENS.HARVARD.EDU