

# Informatics Core Status Report – Collaborative Initiative on Fetal Alcohol Spectrum Disorder

Craig A. Stewart  
stewart@iu.edu

University Information Technology Services, Indiana University

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INDIANA UNIVERSITY

# Personnel and budget changes

- There have been several personnel matters impacting progress of the Informatics Core in the past year.
- These issues have been addressed.
- Cristina Deximo has been hired as a database programmer. She will be dedicated 60% to the Informatics Core overall (100% until the Informatics Core is caught up with all work planned for years one and two).
- Stewart's responsibilities will be returning to the state expected at the time the grant was written.
- The budget has been modified, essentially decreasing the charges to the grant for systems administrators and management, and increasing the programmer effort.

# Specific Aim A1.1 – Progress

- Aim: The Informatics Core will work with CIFASD units to create & disseminate a common data dictionary for data shared within the consortium.
- Progress:
  - 13 areas have been identified as having data that should be stored in the central data repository: Dysmorphology, 3D Facial Imaging, Brain Imaging, Neurobehavioral – Infant, Neurobehavioral – Child, Ultrasound Prenatal, Ultrasound Postnatal, Maternal Prospective, Maternal Retrospective, Cofactors, Lab, Intervention – Child, Intervention – Mother
  - Data dictionaries have been completed for Dysmorphology and 3D Facial Imaging

## Specific Aim 1.2 – Progress

- Aim: The Informatics Core will advise and consult with each of the other CIFRASD participating units so that the data storage mechanisms within each participating unit and facilitate data transmission to the CIFASD Data Repository. The Core will create a manual for the submission of such data.
- Progress:
  - A data input tool was created for the Dysmorphology data
  - The Informatics core has worked with the 3D Facial Imaging Core to help define their procedure for managing data before submission

<b>Field</b>	<b>DataType</b>	<b>ValueRange</b>	<b>Unit</b>	<b>Description</b>
GlobalID	varchar(20)	Legal, capitalized combination of three-letter project identifiers followed by an optional dash followed by a string of numbers, letters and dashes representing a local site ID.		Patient Identification Number
MinimalFrontalBreadth	Float	(.##)	mm	Minimal frontal breadth
BizygomaticBreadth	Float	(.##)	mm	Bizygomatic breadth
BigonialBreadth	Float	(.##)	mm	Bigonial breadth
BitragalBreadth	Float	(.##)	mm	Bitragal breadth
InterocularBreadth	Float	(.##)	mm	Interocular breadth
BiocularBreadth	Float	(.##)	mm	Biocular breadth
RightPalpebralLength	Float	(.##)	mm	Right palpebral fissure length

# Dysmorphology Core Physical Exam Form

ID:

FirstName:

LastName:

Gender:

Birthdate:   
(MM/DD/YYYY)

Click to add a new subject

Enter exam forms below:

Examiner:  Examiner last name:

DateExam:  Number of completed weeks of gestation:   
(MM/DD/YYYY)

If the child is:

< 1 year old

≥ 1 year old

Was the child born prior to 37 weeks of gestation?

If Yes and examined prior to EDC, enter Gestational Weeks at exam:

Months:

If Yes and examined after EDC, enter Adjusted Age:

Months:

Weeks:

If No, Current Age:

Months:

Weeks:

Current Age:

Years:

Months:

### Growth:

13. Height:  cm

16. Weight:  kg

14. Ht%:  15. Ht ≤ 10th Percentile:

17. Wt%:  18. Wt ≤ 10th Percentile:

### Head/Face:

19. Occipite-Frontal Circumference:  cm 20. OFC%:  21. OFC ≤ 10th Percentile:

# Specific Aim 1.1 – Plans

- Aim 1.1: The Informatics Core will work with CIFASD units to create and disseminate a common data dictionary for all data shared within the consortium.
- Plans:
  - Get all caught up
  - Complete all data dictionaries

# Specific Aim 1.2 – Plans

- Aim: The Informatics Core will advise and consult with each of the other CIFRASD participating units so that the data storage mechanisms within each participating unit and facilitate data transmission to the CIFASD Data Repository. The Core will create a manual for the submission of such data.
- Plans:
  - Complete all data entry tools and the data submission manual as quickly as possible (given development of the data definitions by other parts of the consortium – within roughly six weeks +/-)



# Specific Aim 1.3 – Plans

- The Informatics Core will create systems to permit submission of data in an encrypted format via high-speed networks. Data will be verified (according to the parameters identified in the data dictionary) before being added into the CIFASD Data Repository
- Plans
  - Web-based and command-line tools will be created
  - The Dysmorphology Core will be used for prototyping and developing this system

## Specific Aim 2.1 – Plans

- Aim: Data will be maintained in an Internet-accessible, secure database. They will be easily accessible to those properly authorized to receive such data, and data will be delivered in formats specified by the requestor.
- Plans:
  - We will develop the data retrieval facilities immediately after developing the data submission tools for each core.
  - The Dysmorphology Core will serve as the prototype

# Specific Aim 2.2

- Aim: Backup copies of all data will be stored in a secure, robust, long-term storage system
- Plans:
  - All facilities, software, and services required to accomplish this Aim are in place.

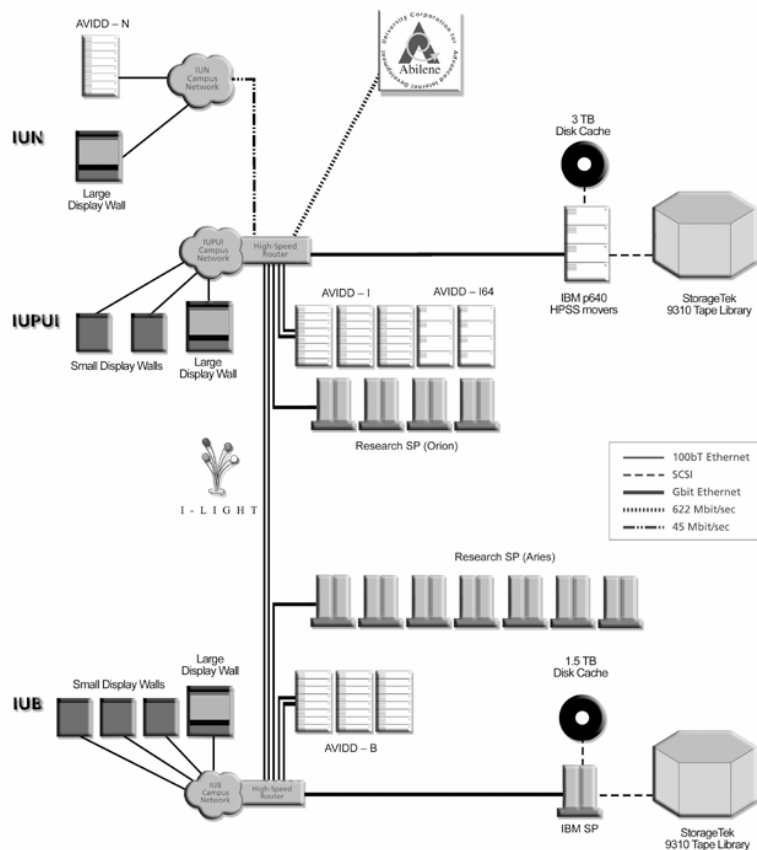


Photo by Tyagen Miller, © Trustees of Indiana University

# Specific Aim 3.1 – Plans

- Aim 3.1 The Informatics Core will provide consulting on experimental design and analysis and ensure that the data are analyzed and scaled in a fashion that makes possible comparisons across the research Programs, Cores, and Pilot Studies
- Plan: Consulting time will be available on request. Contact via email to [CIFASD\\_IC@INDIANA.EDU](mailto:CIFASD_IC@INDIANA.EDU)

## Specific Aim 3.2 – Plans

- Aim 3.2 The Informatics Core will provide consulting on software tools and, where needed, access to computing systems with statistical software available.
- Plans:
  - Accounts on IU systems may be created by sending email to CIFASD\_IC@INDIANA.EDU with the following information: Name, work address & phone #, date of birth, current email address, please indicate whether or not you are a US Citizen, and your university ID number (iff your university does not use SSNs!)
  - Statistical computing help for issues related to this grant are available now, via email (to [statmath@indiana.edu](mailto:statmath@indiana.edu)) or via phone (812-855-4724) are affiliated with CIFASD.

## Aim 4 – Plans

- Aim 4.1 The Informatics Core will provide quarterly summaries of data held in the CIFASD Data Repository, including summaries of new data submitted during the quarter.
  - Plans:
    - The first such summary will be disseminated between 1 and 15 October 2004.
- Aim 4.2 The Informatics Core will provide ad hoc reports for the Administrative Core on request
  - Plans:
    - Reports will be prepared as requested

# Contacting the Informatics Core

- Any question for the Informatics Core may be sent via email to the account CIFASD\_IC@IU.EDU effective 1 July
- A web site will be set up and announced soon.
- Stewart may be contacted as follows:  
stewart@iu.edu; (812)–855–4240 (office); (812)–325–3452 (cell phone, pls only for time–critical issues)
- Arenson may be contacted as follows:  
aarenson@iupui.edu; 317–278–1208